Integration of Palliative Care into the PCMH Model

IMPLEMENTATION TOOLKIT

Intervention #1: Health Care Proxy (Simple Advance Planning)
Last Updated: April 5, 2017

OneCity Health Services | 199 Water Street, 31st Floor, New York, NY 10038
646-694-7090 | ochsupportdesk@nychhc.org
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HOW TO USE THIS IMPLEMENTATION TOOLKIT

This Implementation Toolkit: Integration of Palliative Care into the PCMH Model was developed by OneCity Health to help primary care practices improve the quality of life for their patients with serious illness and their families. This Toolkit explains the services that will be provided through the first intervention of this project, Health Care Proxy (Simple Advance Planning), and provides guidance for primary care practices to integrate brief structured counseling around identifying a Health Care proxy.

The intended audience for this toolkit includes clinical and administrative staff at primary care practices. The quality improvement work included in this Toolkit are consistent with the goals of the Patient Centered Medical Home (PCMH).

This Toolkit is organized into four major sections:

- **Project Overview** – This section provides a summary of the project, state mandated requirements metrics, goals and timeline.

- **Step 1: Preparation** – Current resources and workflows will be assessed and a workgroup will be established.

- **Step 2: Intervention Development** – Workflow changes will be evaluated and a launch timeline will be established.

- **Step 3: Launch, Assess, Scale, and Track** – The workgroup will ensure implementation plans are finalized, workflows are communicated, training needs are met and metrics can be collected and reported to OneCity Health.

*Note: Additional toolkits will provided for subsequent phases of the project.*

SYMBOL KEY

The symbols below are used throughout the document as indicators:

- ![Folder](folder.png) – Key component of project implementation

- ![Exclamation Mark](exclamation.png) – Important implementation consideration
ONECITY HEALTH SUPPORT DESK

If you have any questions, please contact the OneCity Health support desk:

Phone Number: 646-694-7090

Email: ochsupportdesk@nychhc.org, with the subject line “Palliative Care Question”

Hours of Operation: Monday through Friday from 9am to 5pm ET
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Key Tasks Checklist

STEP 1: PREPARATION

<table>
<thead>
<tr>
<th>Key Tasks</th>
<th>Owner</th>
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<tr>
<td>Establish Palliative Care project workgroup</td>
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<td>Review current health care proxy workflows and documentation</td>
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STEP 2: INTERVENTION DEVELOPMENT

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<td>Develop list of staff who will require health proxy training</td>
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<td>Identify relevant resources needed (e.g. health care proxy forms, photocopier, scanning process)</td>
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STEP 3: LAUNCH, SCALE, AND TRACK

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<td>Conduct ongoing quality improvement to assess launched workflow and troubleshoot problems</td>
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OVERVIEW: PALLIATIVE CARE PROJECT

PROJECT OBJECTIVE

The objective of this project is to support primary care teams in enhanced implementation of advance planning, chronic symptom management, and patient-centered approaches to advanced illness management.

The project is comprised of two phases that will provide appropriate levels of care for different populations:

1. Health care proxy (simple advance planning)
2. Enhancing palliative care skills for care teams

This Implementation Toolkit focuses on Phase 1: Health Care Proxy. Additional Toolkits will cover Phase 2.

WHAT IS PALLIATIVE CARE?

Palliative care¹...

- “is care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families.”
- “can be appropriate at any stage of a serious illness.”
- “may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics.”

Center to Advance Palliative Care. The Case for Hospital Palliative Care. 2015.

¹ University of Rochester Medical Center; Duke Center for Learning in Health Care and the Duke Cancer Care Research Program; the American Academy of Hospice and Palliative Medicine; and the Institute of Medicine
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Palliative care has been found to significantly improve mood and quality of life for patients and reduce costs associated with end-of-life care, including hospital admissions, time spent in intensive care units (ICUs), and procedures associated with pain management. Palliative care promotes a patient-centered approach to defining care needs, as illustrated by the “Eight Domains” of Palliative Care:

1. Structure and processes of care (coordinated, interdisciplinary, collaborative, continuous);
2. Physical aspects of care (symptom management);
3. Psychological and psychiatric aspects of care;
4. Social aspects of care;
5. Spiritual, religious, and existential aspects of care;
6. Cultural aspects of care;
7. Care of the patient at the end of life; and
8. Ethical and legal aspects of care

Advance care planning is a central component of palliative care and is a process that enables individuals to make plans about their future health care. Advance care plans provide direction to healthcare professionals when a person is not in a position to either make and/or communicate their own healthcare choices. Participation in advance care planning has been shown to reduce stress and anxiety for patients and their families, and lead to improvements in end of life care. Health care proxies are one form of advance care planning, in which the patient names a proxy to make medical decisions for the patient should the patient lose the ability to make his or her own decisions.

WHAT IS PRIMARY PALLIATIVE CARE?

The goal of integrating palliative care into primary care would be to address patients’ needs in a trusted setting where they receive most of their care. Primary care teams are responsible for much of a patient’s health care, and these teams form strong relationships with patients based on years of care. Teaming with primary care to provide earlier palliative care may address gaps in care planning and symptom management for patients with serious illness.

Primary palliative care is provided by non-specialists and may include:

✓ identification of patients who would benefit from primary palliative care
✓ basic management of symptoms including pain
✓ management of psychological and psychiatric sources of distress
✓ goal setting and advance planning discussions including prognosis and treatment goals
✓ connection to social services, home care, transportation, etc. as needed to address

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- Social and functional needs
- Referrals to specialty palliative care when needed (e.g., complex or recalcitrant pain management, management of conflicts within families, management of the period when death is foreseen)

Primary care practices may encounter challenges when incorporating palliative care into clinical practice due to short visits, workflow changes and data collection needs (e.g., filing of advance directive documents), multiple care transitions, and the need to establish new referral patterns. OneCity Health will support primary care practices in overcoming these challenges by providing standardized training and materials to members of the care team, and resources to implement sustainable and effective workflow changes.
CLASSIFICATION: INTERVENTION #1 - HEALTH CARE PROXY AND SIMPLE ADVANCE PLANNING

WHAT IS A HEALTH CARE PROXY?

The New York Health Care Proxy Law allows individuals to appoint someone they trust — for example, a family member or close friend — to make health care decisions if they lose the ability to make decisions for themselves. By appointing a health care agent, individuals can make sure that health care providers follow their wishes. Use of a Health Care Proxy form to appoint one’s Health Care Agent is recommended for all adults, ages 18 and above, healthy or sick.

Health care proxies can make medical decisions only if the patient is unable to make them for him- or herself. The health care proxy does NOT have the ability to obtain medical information or make decisions for a patient who is able to make his or her own decisions. A health care proxy cannot make legal or financial decisions, only decisions related to the patient’s medical care. The patient can change his or her mind and appoint a new health care proxy at any time.

Even if the patient loses capacity, the health care proxy cannot address issues such as financial management or custody of minor children. If your patient requests assistance in planning for these issues, patients seeking additional legal support can be referred to LegalHealth (http://legalhealth.org or (212) 946-0357) for free legal assistance for low-income New Yorkers with serious health problems across New York City.

WHY IS A HEALTH CARE PROXY IMPORTANT?

Naming a proxy early will help prepare for the unexpected. Everyone should consider doing a health care proxy because the designated person will be able to make judgments based on the most current situation and information. Discussions between a clinician and patient about designating a health care proxy provides an opportunity for the clinician to learn what matters most to their patient. Discussions involving just a few important questions often unlock a better understating of patient goals, preferences and values.

OBJECTIVE: INTERVENTION #1

Patients will designate a health care proxy after engaging in brief structured counseling from the Patient Centered Medical Home (PCMH) team. This counseling will include why a proxy is important, factors in considering proxy selection, and how to discuss values, preferences, and goals with the selected health care proxy. The structured counseling is a critical component of simple advance planning and will support the patient to make an informed decision.

TARGET POPULATION

All adult patients are appropriate for the health care proxy intervention. Use of a NYS Health Care Proxy Form to appoint one’s Health Care Agent is recommended for all adults, ages 18 and above, healthy or sick. Some clinics may choose to design their workflows in a way that focuses their efforts in health care proxies on patients who are older or who are chronically ill. Other clinics may wish to design workflows that capture all adult patients.
STEP 1: PREPARATION – INTERVENTION #1

The main goals of this preparation stage are:

1. Establish Palliative Care Project Workgroup
2. Palliative Care Workgroup holds kickoff meeting and reviews care model
3. Review current health care proxy workflows and documentation

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<thead>
<tr>
<th>Key Tasks</th>
<th>Implementation Toolkit Resources</th>
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</table>
| Establish Palliative Care project workgroup | ☐ Establish Palliative Care Project Workgroup  
☐ Appendix A: Implementation Templates |
| Palliative Care Workgroup kickoff meeting to review care model and identify responsibilities and next steps | ☐ Palliative Care Kick-off Meeting Slide Deck |
| Review current health care proxy workflows and documentation | ☐ Mapping Current Workflows  
☐ Appendix A: Implementation Templates |
Establish Palliative Care Project Workgroup

Before starting project planning and implementation, a Palliative Care Workgroup should be established if appropriate for your practice. The workgroup is responsible for key tasks and deliverables such as mapping workflows, identifying training needs, and quality improvement.

The size of the workgroup will depend on the size of your practice. Smaller practices may opt not to create a workgroup. The workgroup should be organized by an implementation lead and should include a clinical champion.

Palliative Care Workgroup: The workgroup should include essential clinical, administrative, health information technology and other individuals you think will be critical to your success in implementing this project. The workgroup can identify additional members to consult for specific issues at each intervention stage. Consider representatives from these areas:

- Administrative and non-clinical staff
- Physicians
- Nursing
- Social work
- Care Management
- Patient/Family representatives
- Information technology

Implementation Leader: Identify an implementation leader to facilitate local implementation planning. Specific tasks include:

- Identifying workgroup and facilitating meetings to achieve goals as described in toolkit
- Engaging with clinical and administrative leadership to advocate for implementation and to provide progress updates and reports
- Collaborating with OneCity Health to access implementation support and materials
- Ensuring that there is a training plan in place at the site and individuals who need to be trained have time to attend trainings
- Monitoring and troubleshooting implementation

Clinical Champion(s): Local clinical champion(s) are crucial for the success of the implementation and must be well-positioned and able to engage, educate and lead others in the site-level implementation. Consider clinical champions from each discipline (e.g. RN, MD, SW) to ensure the interdisciplinary approach to the palliative care project. Clinical champions should practice in the setting where the palliative care project will be implemented. Specific activities of the champion include:

- Engaging and advocating for palliative care project implementation with clinical leaders
- Collaborating with clinical staff to ensure they have the tools and resources needed
- Eliciting and representing clinical team’s knowledge on patient and site needs
- Working closely with the implementation leader to ensure that the necessary training and support, including staff time to implement, is in place
- Eliciting feedback from clinical staff on successes and areas for improvement
Mapping Current Workflows

A better understanding of current workflows will help the Palliative Care Workgroup to identify process and resource gaps and assess potential areas for improvement.

⚠️ For each workflow, please ensure sign off is received from two frontline staff members who have direct roles in the workflow.

By observing existing workflows in person, areas for improvement can be identified to incorporate administering a health care proxy as a standard part of work in the primary care practice.

**RESOURCES ON MAPPING WORKFLOWS**

Institute for Healthcare Improvement, Flowchart

STEP 2: INTERVENTION DEVELOPMENT

The main goals of this intervention development stage are:

1. Map revised workflows
2. Acquire appropriate resources if necessary
3. Determine training needs
4. Create a timeline for launch

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| Develop revised workflow for identification of patient for health care proxy intervention and conducting intervention (review guiding questions and sample workflow for guidance) | ❑ Considerations and Guiding Questions for Developing Health Care Proxy Workflows
❑ Sample Workflow #1: Patients in a Disease Management Program
❑ Sample Workflow #2: All Patients
❑ Appendix A: Revised Workflow Mapping Template – Intervention #1 |
| Determine standardized documentation of completed health care proxy and notes from the conversation | |
| Review revised workflow with appropriate staff (not just Palliative Care Workgroup) to ensure all staff understand the new workflow | |
| Develop list of staff who will require health proxy training | ❑ Staff List for Health Care Proxy Training Template |
| Identify relevant resources needed (e.g. health care proxy forms, photocopier, scanning process) | ❑ Pre-launch Checklist |
Steps for mapping a revised workflow:

Workflows must include: (1) the provision of structured counseling (includes explaining use of a health care proxy form and advising patient on considerations in choosing a health care proxy), and (2) a process to scan or otherwise keep in Electronic Health Record a copy of completed health care proxy forms.

1. Consider any Current State Workflows identified when mapping Revised Workflows.

2. Determine target population at your site. It is recommended to start with a pilot population before expanding to all adult patients. In previous implementations, several practices started their implementation efforts by focusing on a clinic (e.g., HIV) or a patient population (e.g., new patients). Others started with a few PMCH teams before expanding to all of them. This allowed them to test new workflows and troubleshoot any problems before expanding to a larger scale.
   - Example: all patients 18 years old and older
   - Example: all new patients
   - Example: all patients with diabetes or hypertension
   - Example: all patients 55 years old and older
   - Example: patients referred by nursing/physician staff
   - Example: HIV Clinic

3. Determine how target population will be identified.
   - Example: all patients on registration, or patients >55 on registration
   - Example: patients seeing diabetes educator or in disease management program
   - Example: nursing or physician referral

4. Map current workflows relevant to target population.

5. Adjust workflow to take into account new health care proxy intervention.

6. Define staffing roles in new intervention.

Revised workflows may entail mapping out roles of different staff members within the primary care team. For each workflow, please ensure sign off is received from two frontline staff members who have direct roles in the workflow.
Guiding questions for workflow development:

1. Patient selection
   - Which existing workflows can be used to discuss health care proxies?
   - Which patients would be impacted by these workflows and how often?

2. Staff and workflow
   - Where will the blank health care proxy forms be kept and in which languages?
   - What will trigger a clinician to discuss a health care proxy with a patient? To whom do patients usually express preferences or discuss personal medical information?
   - Where will the health care proxy conversation be conducted?
   - When will the health care proxy form actually be filled out?
   - Who will make two copies of the form? The patient should receive two copies of the completed health care proxy form (one to keep, one to give to their proxy).
   - The health care proxy requires two signatures. Who will be those two signatures?
   - If a patient does not want to select a health care proxy, what will happen? Will the physician be involved? How will this be documented?
   - If staff have questions about the health care proxy workflow or forms, who should they be directed to?

3. Documentation and storage
   - Where will the scanned copy of the completed health care proxy form be saved in the EMR? What naming convention will they follow?
   - How/where are discussions documented in the EMR? How will they be documented consistently?
   - How will the number and quality of completed health care proxy forms be monitored?

4. Tracking
   - Approximately how many patients will be engaged on a weekly basis?
   - How will the number of patients with health care proxies be tracked?
   - What OneCity Health support is needed for metrics and data tracking?
   - What is the process to monitor weekly progress and provide any feedback to improve performance?

5. Training needs
   - How many staff members will be trained and able to administer the health care proxy form? What is the plan if that individual goes on vacation?
   - By what means will clinic staff in general be informed as to this intervention

6. Resources/materials/supplies/equipment
   - What existing educational materials for patients (Appendix B) should be made available to patients? Where will these be located?
   - Are all the equipment and tools necessary to implement the health care proxy form available and working (e.g. a scanner, copy machine, etc.)?
Sample Workflow #1: Patients in a Disease Management Program

Patient has existing completed health care proxy form in the EMR?

- No
  - RN initiates structured counseling and provides additional educational materials as appropriate
  - Patient needs more time to decide
    - No
      - Patient selects health care proxy, completes form, and both patient and RN sign the form
    - Yes
      - RN notes that patient already has a healthcare proxy, RN reviews with patient, and makes any necessary changes
  - Yes
    - RN schedules f/u and makes note to discuss again
      - At f/u appointment, RN discusses proxy again and signs
        - RN brings document to administrator who provides a second witness signature, makes 2 copies and scans the form into the EMR
          - RN documents discussion in notes for the visit and patient receives two paper copies of the new/updated proxy to take home
Sample Workflow #2: All Patients

Patient has existing completed health care proxy form in the EMR?

- No
  - Nurse notes that patient already has a healthcare proxy and flags for MD. MD reviews with patient to make necessary changes.
  - No
    - Patient selects health care proxy, completes the form, and both patient and MD sign the form.
    - Patient needs more support to decide
      - Yes
        - MD sends patient to SW for further discussion
      - No
        - Patient select health care proxy, completes the form, both patient and SW sign the form
          - Yes
            - Nurse provides a second witness signature, makes 2 copies and scans the form into the EMR
            - MD documents discussion in notes for the visit and patient receives two paper copies of the new/updated proxy to take home
          - No
            - The MD initiates structured counseling and provides additional educational materials.
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STEP 3: LAUNCH, ASSESS, SCALE AND TRACK

The main goals of this Launch, Assess, Scale & Track stage are:

1. Appropriate staff completes health proxy training
2. Launch proposed workflow
3. Regularly monitor workflow and modify as necessary

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<td>Schedule regular check-in meetings for the Palliative Care Workgroup or add to the standing agenda of an existing meeting to track progress</td>
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## Pre-launch checklist

- Have all key personnel participated in training?
- Are all key personnel aware of health care proxy policies and procedures, particularly as they relate to signatures and documentation?
- Has an adequate supply of health care proxy forms been made available to staff?
- Are all staff aware of where documents are kept? (e.g. patient education materials, blank health care proxy forms)
- Do all staff know who to contact if they have questions about the health care proxy forms or process?
- Has the program been communicated to all staff in a variety of methods (e.g. in person meetings, memos, etc.)?
- Are all staff aware of go-live date?
- Is there a plan to elicit feedback from front-line staff in the first days of implementation, and to use this to inform PDSA cycles?
- Is there a plan to elicit feedback and improve implementation over the following weeks to months?
- Are staff aware of how completed health care proxies are being documented and tracked?
- Has staff been briefed on new EMR procedure?
Checklist for Administering a Health Care Proxy Form

When a patient comes in:

- Ask if they have a health care proxy
- Initiate structured counseling and review health care proxy form
- Write down name of health care proxy and complete form
- Have patient sign form
- Sign form as first witness signature

Before patient leaves:

- If a patient has not completed the form, determine next steps for follow up or further counseling
- Administrator provides second designated signature on health care proxy form
- Make two copies of health care proxy form
- Give patient two copies of health care proxy form and additional education materials
- Scan original of form into EMR
## APPENDIX A: IMPLEMENTATION TEMPLATES

### Palliative Care Workgroup Template

**Instructions:** Please complete the following template to identify your Palliative Care Workgroup with your OneCity Health Hub Executive Director or Project Manager.

<table>
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<th>Implementation Lead:</th>
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</tbody>
</table>
### Current Workflow Mapping Template: Intervention 1 – Health Care Proxy

**Instructions:** Please map the **CURRENT** workflow for a patient’s experience with brief counseling around designating a health care proxy and appropriate documentation.

<table>
<thead>
<tr>
<th>Facility Name:</th>
<th>Implementation Leader:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
<td></td>
</tr>
</tbody>
</table>

Insert workflow chart here or provide as an attachment.

**Gaps Identified:**

**Resource Needs:**

Sign-off from at least two frontline staff members that have direct roles in the workflow is required for each:

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Signature</th>
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</thead>
<tbody>
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</tbody>
</table>
# Health Care Proxy Documentation Assessment Template

**Instructions:** Please assess your current documentation of health care proxies by answering the questions below.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Site Name:</td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
</tr>
<tr>
<td>1. How is your site currently documenting if a patient has a health care proxy?</td>
<td></td>
</tr>
</tbody>
</table>
| 2. Where is a scanned copy of the completed health care proxy form stored for each patient (e.g. field(s) in EMR)?  
*The completed health care proxy form should be clearly and easily accessible in the EMR.* |   |
| 3. Who has access to the health care proxy field(s) in the EMR?  
*Appropriate staff should be able to document conversations and completed forms in the EMR.* |   |
| 4. How can your site track the number of patients with a completed health care proxy form (e.g. EMR reports or a tracking spreadsheet)? |   |

<table>
<thead>
<tr>
<th>Name:</th>
<th>Title:</th>
<th>Signature:</th>
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### Revised Workflow Mapping Template – Intervention #1

**Instructions:** Please map the *REVISED* workflow for a patient’s experience with brief counseling around designating a health care proxy and appropriate documentation.

<table>
<thead>
<tr>
<th>Facility Name:</th>
<th>Implementation Leader:</th>
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</thead>
<tbody>
<tr>
<td>Date:</td>
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</table>

Insert workflow chart here or provide as an attachment.

**Gaps Identified:**

**Resource Needs:**

**Sign-off from at least two frontline staff members that have direct roles in the workflow is required for each:**

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<thead>
<tr>
<th>Name</th>
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</table>
### Staff List for Health Care Proxy Training Template

**Instructions:** OneCity Health will provide training materials and a webinar for practices to use for training their primary care team members. Please identify and document staff members from the primary care team that received training on conducting structured conversations about health care proxies. Consider using existing training venues or opportunities. OneCity Health may request attendance sheets.

<table>
<thead>
<tr>
<th>Site Name:</th>
<th>Training Date:</th>
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<table>
<thead>
<tr>
<th>Name</th>
<th>Department</th>
<th>Title</th>
<th>Discipline</th>
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</table>
Implementation Toolkit: Integration of Palliative Care into the PCMH Model

Implementation Best Practices (gathered from pilot sites)

1. ENGAGE YOUR CHAMPIONS

Make sure you have the right people in your project implementation workgroup.

Practices reported the value of a variety of clinical and administrative champions from an operational, physician, nursing, and social work perspectives. The champions should be embedded in the daily practice of the primary care practices. This ensures that administrative, operational and clinical workflows are supporting the necessary work and the best people for each role are identified.

One practice suggested presenting the project objectives and framework to the primary care physicians to determine which physicians are more interested in being champions. Even if other primary care team members are involved with the majority of health care proxy conversations, the reinforcement from physicians will help them succeed.

Some practices involved team members focused on other chronic disease initiatives such as the depression collaborative care team. Practices suggested getting as many people involved up front as possible to increase staff buy-in.

2. OBSERVE EXISTING WORKFLOWS TO IDENTIFY GAPS

Look at where a health care proxy is currently being administered and identify gaps and an action plan to address those gaps.

Common implementation challenges related to workflows were lack of time in patient visit to discuss healthcare proxy and patient not completing healthcare proxy during one visit. Several approaches were taken to utilize the pre-visit waiting time for patient education:

- Post flyers at front desk or waiting room table introducing health care proxy
- Include healthcare proxy education handout along with new patient paperwork during registration
- Send trained staff to round in the waiting room
- Encourage patient to discuss the healthcare proxy with clinical team
- Add a health care proxy question to the patient medical history/intake form

All patients may not complete a health care proxy while they wait for the visit, so the following approaches may be used to maximize the time during or after the visit:

- Health care proxy conversation incorporated into annual visits
- Physician/NP refers patient to social worker, case manager, or care coordinator to have in depth conversation immediately after the visit
3. ENSURE ROBUST TRAINING FOR MULTIPLE PROVIDER AND ADMINISTRATIVE TYPES

Training generates staff buy in. After being trained staff are saying, “I need a healthcare proxy! Everyone needs a healthcare proxy!”

Training staff from different roles in the primary care team creates a shared vision for the project. Practices that require staff training were able to train a broader range of staff and make it clear that the health care proxy was a part of standard work. The training gave people the opportunity to talk about personal experiences and buy into the importance of the project for their patients.

Practices identified several venues for training and generating staff buy in:

- Presenting at nursing rounds
- Providing positive feedback to staff once they begin having health care proxy conversations with patients
- Train the staff in the clinics 1-on-1 with role playing. Going through the form as if they were filling out with themselves and answering FAQs. Staff were supported by the social worker to answer any follow up questions.
- Bring in champions from other clinics that have started the work to demonstrate project successes

4. START SMALL AND BUILD ON SUCCESSES

By testing your intervention on a small scale, you have the chance to iterate and problem solve.

Several practices started their implementation efforts by focusing on a clinic (e.g. HIV) or a patient population (e.g. new patients). Others started with a few primary care teams before expanding to all of them. This allowed them to test new workflows and troubleshoot any problems before expanding to a larger scale.

5. DOCUMENTATION

Understanding how the health care proxy form was documented and running routine reports allowed practices to track their project implementation.

Practices devoted time to understating how health care proxy forms were documented in the medical record and the workflows for scanning and copying the form. It was essential to confirm that key primary team members had appropriate access to and the ability to modify this information in the EMR.

Once the workflows for documentation were established, the project implementation workgroup was then able to monitor the volume of patients reached by the intervention through routine reports. Practices also reviewed the reports and completed health care proxy forms for quality.
APPENDIX B: CONVERSATION GUIDE – HEALTH CARE PROXY

This guide was designed to help you start the conversation and support your patient in their decision to designate a health care proxy. Additional clinician education and support materials can be found in Appendix B.

Goals of the conversation:

- Educate the patient about health care proxies.
- Identify a health care proxy, if the patient is ready to do so; if not, then provide guidance on selecting a health care proxy, a health care proxy form, and instructions for returning a copy to the clinic.
- Provide coaching to the patient as to discussion of values, goals, and preferences with health care proxy.

STEP 1: INTRODUCE THE TOPIC

Signal a new topic

Signal to the patient that you would like to discuss something that the patient may not have been expecting for this visit, “Can I put something else on our agenda today?” Signposting helps your patient realize that you’re changing topics, and gives him or her a chance to finish up—for example, to say, “Oh, could I ask a question about my pain first?”

Introduce the topic

When beginning a discussion of a health care proxy simply ask, “Do you know what a health care proxy is? Do you have one?”

If you are afraid the patient may respond negatively, perhaps saying to you “Is there something wrong with me? Am I sicker than you are letting on?” respond by saying, “I ask all of my patients this question, sick or well: the best time to start thinking about this is before something serious occurs.”

Ask for permission to discuss appointing a health care proxy

If the patient does not have a health care proxy, you can ‘normalize’ that she doesn’t have one and ask permission to explain why she may want to consider appointing one by saying, “Most people don’t have one but this is something I discuss with all my patients. Can I take a minute

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5 Education for Physicians on End-of-life Care (EPEC) Handbook – Module 1: Advance Care Planning
http://library.nymc.edu/Intranet/Ppt/E-Slides%20Module%201.ppt
NYC Health Information: Improving Palliative Care at the End of Life
Implementation Toolkit: Integration of Palliative Care into the PCMH Model

to explain why it’s worth thinking about?”

**STEP 2: EXPLAIN WHY A HEALTH CARE PROXY IS IMPORTANT**

When patients sound uncertain about a health care proxy, slow down and attend to your patient’s uncertainty.

“There may be periods, in which you may not be able to make medical decisions for yourself. It’s important to think of someone you can trust that will be able to share your preferences and what is most important to you if there is a medical decision needed and you couldn’t talk to the doctors.”

**STEP 3: ELICIT PATIENT VALUES, GOALS AND PREFERENCES**

Ask open-ended questions:
- “What is most important to you in your life right now?”
- “What are your most important hopes?”
- “What do you hope to avoid most of all?”

Ask about past experiences, either the patient’s own or those of other people the patient knows.

“Can you tell me about experiences you or someone you know has had making health care decisions for a loved one?”

Describe possible scenarios and ask the patient what he or she would want in such a situation

Ask patients which options they prefer:
- Attempt cure; use all appropriate interventions.
- Give curative treatments where appropriate and manage other conditions; avoid aggressive interventions.
- Keep me comfortable and emphasize quality of what time remains; avoid potentially life prolonging interventions.

**STEP 4: DISCUSS POTENTIAL INDIVIDUALS TO DESIGNATE AS A HEALTH CARE PROXY**

“I also like to ask my patients if they have someone they would like to identify to act on their behalf if something happens and if they are unable to express their own wishes. This person could be a relative or a friend. Is there someone you would want to be part of our discussion and have act on your behalf?”

**STEP 5: SUMMARIZE NEXT STEPS**
Communicating health care preference to the proxy

The goal is for the proxy to understand the patient’s values and begin thinking with the patient about the future in a non-threatening way.

“Naming your health care proxy is the first step. We will give you a copy of this form so you can share it with them. It is important that you also talk to your health care proxy about your health care preferences now so they are able to make the best decisions on your behalf:

1. What are your goals if your health worsens? What is most important to you?
2. What are your fears?
3. What trade-offs are you willing to make and not willing to make?”

Close the conversation
- Ask the patient to repeat back his or her understanding of what was discussed and the next steps
- Express your appreciation for their willingness to talk about the topic
- Stress that this is an ongoing conversation and changes to the proxy can be made in the future

STEP 6: DOCUMENT THE CONVERSATION AND ANY DECISIONS MADE OR STILL PENDING
- Be sure to document your conversation; make notes for the chart. Clearly state the context for the discussion and any decisions made or still pending
- Advise the patient to have a copy of the form(s) at home and to give copies to his or her proxy and all of his or her health care providers (in both outpatient and inpatient settings)

CULTURAL COMPETENCY

Culture is especially important in medical decision-making and often informs the meaning patients and families attach to these decisions. Considerations include:
- **Linguistic barriers and medical literacy**: If there is a language barrier, try to use a professional interpreter rather than a family member; this helps to avoid role changes that may be uncomfortable for the family and ensures that communication is unfiltered
- **Alternative medical traditions**: Remedies common to the patient’s culture may provide important sources of comfort in an illness. Try to accommodate traditional remedies if they are not harmful.
- **Cultural values**: Autonomy is often important to individuals, but others may emphasize matriarchal or patriarchal roles in their family and have different approaches to conveying medical information and decision-making
Simply ask open-ended questions about beliefs that may be prevalent within a culture, rather than making assumptions:

- “How do you like to handle important information about your medical care?”
- “What helps you in this kind of situation?”

**RESPONSES TO CONCERNS PATIENTS MIGHT EXPRESS**

1. **I am worried that if I name a proxy, I will lose control of my own care.**

   “Many people have the same concern. However, you will always retain medical decision-making capacity. Advance directives only become active when a person cannot speak for him or herself.”

2. **I’m too young to be thinking about something like this.**

   “The stakes may actually be higher for younger people if tragedy strikes. If there was ever an accident that led to a situation that may leave you unable to make health care decisions for a period of time, who would you want to make decisions about your medical care if you were in this situation?”

3. **I am feeling fine, so we don’t need to talk about this now. We can wait and handle things as they come up.**

   “We’d both like to think that you will always be healthy and able to make decisions for yourself. But things can happen suddenly. Things can change. You might have an accident or develop a serious condition and not be able to speak for yourself. So, making your wishes known now will help everyone, including the doctors, be able to care for you the way you want.”

4. **There is no need to talk about this because “The doctor will make the decisions anyway,” or “I trust my family to know what to do,” or “It’s all in God’s hands anyway...”**

   “Though your doctor will help, she or he will still turn to your health care proxy to make the choices for you. It will be very difficult for your family to know what to do if you haven’t talked about your wishes with your family. And, it puts a real burden on those who have to make decisions on your behalf when they aren’t sure what you would want.”

5. **This is too hard (or morbid or depressing) to talk about.”**

   “While it can be hard to talk about, it’s very important for your family. If they have to guess what you would like, they might feel anxious about making the right decision. And, they may disagree and not know what to do. Talking about this now will help all of
us do a better job taking care of you just in case it becomes necessary.”

6. “I’m glad you brought this topic up, I should have a plan for my children in case something ever happens to me.”

“A health care proxy is one part of planning for the future. A health care proxy cannot make legal or financial decisions, only decisions related to medical care. I suggest making additional legal and financial arrangements for your children and I can connect you to resources that can help.”

Patients seeking additional legal support can be referred to LegalHealth (http://legalhealth.org or (212) 946-0357) for free legal assistance for low-income New Yorkers with serious health problems across New York City.
New York State Health Proxy Resources

Order health care proxy forms for free of charge from the New York State Department of Health: [https://www.health.ny.gov/forms/order_forms/health_care_proxy.pdf](https://www.health.ny.gov/forms/order_forms/health_care_proxy.pdf)

Download health care proxy forms from the New York State Department of Health: [https://www.health.ny.gov/professionals/patients/health_care_proxy/](https://www.health.ny.gov/professionals/patients/health_care_proxy/)

The New York Health Care Proxy form and instructions are available in the following languages:

- **English** (PDF)
- **Chinese** (PDF)
- **Haitian Creole** (PDF)
- **Italian** (PDF)
- **Korean** (PDF)
- **Russian** (PDF)
- **Spanish** (PDF)

NYC Health and Hospitals translated the New York Health Care Proxy form into the following additional languages:

- Albanian (PDF) [http://clas.nychhc.org/Uploads/doh-1430_Albanian.pdf](http://clas.nychhc.org/Uploads/doh-1430_Albanian.pdf)
- Arabic (PDF) [http://clas.nychhc.org/Uploads/doh-1430_Arabic.pdf](http://clas.nychhc.org/Uploads/doh-1430_Arabic.pdf)
Clinician Education & Support

- Health Literacy Thesaurus
  National Partnership for Women and Families
- NURSE statements for articulating empathy
  Vital Talk
  http://www.vitaltalk.org/sites/default/files/NURSEforVitaltalkV1.0.pdf
- Advance Care Planning – Online Courses
  Respecting Choices
  http://www.gundersenhealth.org/respecting-choices/training-and-certification/online-courses

Patient Education

- Advance Care Planning Booklet
  Compassion and Support
  http://www.compassionandsupport.org/pdfs/about/B-1576_Excellus_2010_Complete.pdf
- Advance Care Planning for Patients and Families
  Compassion and Support
  http://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning
- Conversation Starter Kit
  The Conversation Project
  http://theconversationproject.org/starter-kit/intro/
- Cultural Competency Outreach Guides
  National Hospice and Palliative Care Organization
  http://www.nhpco.org/access
- Five Easy Steps: Advance Care Planning
  Compassion and Support
  http://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning/discuss_your_wishes
- Guide for Health Care Agents
  Coalition of Compassionate Care of California
- How to Clarify Your Values and Beliefs
  Compassion and Support
  http://www.compassionandsupport.org/pdfs/about/Clarify_Values_and_Beliefs.pdf
- Offering Spiritual Care and Support
Implementation Toolkit: Integration of Palliative Care into the PCMH Model

- PREPARE: Choose a Medical Decision Maker – an online tool
  https://www.prepareforyourcare.org/
- Selecting a Healthcare Agent
  National Hospice and Palliative Care Organization
  http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3286

Impact of Advance Care Planning

- Value Snapshot: Advance Care Planning
- The Best Possible Day by Atul Gawande

APPENDIX D: GLOSSARY OF TERMS – ADVANCE CARE PLANNING

Adapted from MOLST in Massachusetts Expansion Project Tool Kit, rev. July 2013.

Advance care planning (ACP) is an ongoing process of discussing and clarifying the current state

6 http://molst-ma.org/sites/molst-ma.org/files/Complete%20Tool%20Kit%20Step%201%20-%203%20July%202013.final_.pdf
of a person’s goals, values and preferences for future medical care. The discussion often, but not always, leads to the signing of documents known as advance directives.

**Advance directive (AD)** is a general term referring to a written document for future medical care in the event that a person loses capacity to make health care decisions (i.e. becomes “incapacitated”). It sometimes results from the process known as advance care planning. A health care proxy or a living will is considered to be an advance directive.

**Artificial hydration and nutrition (AHN)** is a medical treatment that supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and/or fluids through a tube placed directly into the digestive tract (enteral); or through a tube directly into a vein (parenteral).

**Cardio-pulmonary resuscitation (CPR)** is a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing. Such procedures may include pressing on the chest to mimic the heart’s functions and cause blood to circulate; insertion of an airway into the mouth and throat, or insertion of a tube into the windpipe; artificial ventilation such as mouth-to-mouth or other mechanically assisted breathing; the use of drugs to stimulate the heart; and/or electric shock (defibrillation) to stimulate the heart. CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness.

**Comfort Care/Do Not Resuscitate Verification protocol (CC/DNR)** is followed by emergency medical service (EMS) personnel when encountering an authorized CC/DNR Verification Form outside of a hospital setting. The CC/DNR protocol directs that a patient in respiratory or cardiac distress be made as comfortable as possible, but that no resuscitative measures be attempted.

**Decision-making capacity** refers to the ability to make and communicate meaningful decisions based upon an understanding of the relevant information about options and consideration of the risks, benefits, and consequences of the decision. The ability to understand other unrelated concepts is not relevant. Capacity can vary according to the task: it may be possible for an individual to appoint a health care agent, for example, yet not make a decision about a medical procedure. Capacity should be assessed routinely, and it is not the same as competence, which is a legal determination made in court.

**Dialysis** is the process of filtering the blood through a machine via two small tubes inserted into the body in order to remove waste products from the body in the way that the kidneys normally do. Dialysis can be done temporarily in order to allow the kidneys time to heal or it can be done on a longer term basis in order to prolong life.
Do Not Hospitalize orders (DNH) are medical orders signed by a physician that instruct health care providers not to transfer a patient from a setting such as a nursing facility (or one’s home) to the hospital unless needed for comfort.

Do Not Intubate orders (DNI) are medical orders signed by a physician that instruct health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress.

Do Not Resuscitate orders (DNR) are medical orders signed by a physician that instruct health care providers not to attempt cardiopulmonary resuscitation (CPR) in the event of cardiac and respiratory arrest.

Durable Power of Attorney for Health Care is a term used in some states for a health care proxy. (See definition below.)

Health care agent is a trusted person, officially appointed, who speaks on behalf of a person 18 years of age or older who is unable to make or communicate health care decisions. This person is appointed in advance via a health care proxy. The agent is called upon only if the doctor determines in writing that a patient lacks capacity to make health care decisions. Unless otherwise limited by the person, the agent has all the rights that the patient has with regard to medical decision-making, including the rights to refuse treatment, to agree to treatment, or to have treatment withdrawn. Decisions should first be made based on the patient’s stated wishes, if known; or if unknown, an interpretation of what the patient would have wanted; or finally, an assessment of the patient’s best interest.

Health care proxy (HCP) is a document in which a person appoints a health care agent to make future medical decisions in the event that the person becomes incapacitated.

Hospice is a philosophy of holistic end of life care and a program model for delivering comprehensive palliative care to persons who are in the final stages of terminal illness and their loved ones in the home or a home-like setting. Hospice provides palliative care in the last months of life. It involves a team-oriented approach that is tailored to the specific physical, psycho-social and spiritual needs of the person and includes support to the family during the dying process. Hospice also provides bereavement support after death occurs.

Life-sustaining treatment refers to medical procedures such as cardio-pulmonary resuscitation, artificial hydration and nutrition, and other medical treatments intended to prolong life by supporting an essential function of the body in order to keep a person alive when the body is not able to function on its own.

Living will (LW) is a document in which a person specifies future medical treatments in the event of incapacity, usually at end of life or if one becomes permanently unconscious, in a persistent vegetative state or “beyond reasonable hope of recovery.”
Medical (or Physician’s) Orders for Life-Sustaining Treatment (MOLST /POLST) is a document intended for seriously ill patients that stipulates wishes for life-sustaining treatment based on the patient’s current condition. A MOLST form becomes effective immediately upon signing and is not dependent upon a person’s loss of capacity. It does not take the place of a health care proxy. Consideration of MOLST may be an outcome of the advance care planning process.

Palliative care is a comprehensive approach to treating serious illness that focuses on the physical, psycho-social and spiritual needs of the patient. The goal of palliative care is to prevent and relieve suffering and to support the best quality of life for patients and their families through such interventions as managing pain and other uncomfortable symptoms, assisting with difficult decision making, and providing support, regardless of whether or not a patient chooses to continue curative, aggressive medical treatment.
APPENDIX E: QUALITY IMPROVEMENT RESOURCES

Plan, Do, Study, Act (PDSA) Cycles

The Plan-Do-Study-Act (PDSA) cycle is part of the Institute for Healthcare Improvement Model for Improvement, a simple yet powerful tool for accelerating quality improvement. Once a team has set an aim, established its membership, and developed measures to determine whether a change leads to an improvement, the next step is to test a change in the real work setting. The PDSA cycle is shorthand for testing a change—by planning it, trying it, observing the results, and acting on what is learned. This is the scientific method, used for action-oriented learning.

The steps in the PDSA cycle are:

- **Step 1: Plan**—Plan the test or observation, including a plan for collecting data
- **Step 2: Do**—Try out the test on a small scale
- **Step 3: Study**—Set aside time to analyze the data and study the results
- **Step 4: Act**—Refine the change, based on what was learned from the test

For more information:
http://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementTestingChanges.aspx

---

PDSA Worksheet for Testing Change – Health Care Proxy Workflow

**AIM**

By [Date], the clinic team at [Site Name] will administer health care proxies with structured counseling to [Number of Pilot Patients].

<table>
<thead>
<tr>
<th>PDSA Cycle # 1</th>
<th>Person(s) Responsible</th>
<th>When to complete</th>
<th>Where to complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Every Aim will require multiple small tests of change)</td>
<td>Describe your test of change:</td>
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<td></td>
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</tbody>
</table>

**PLAN**

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<th>List the tasks needed to set up this test of change</th>
<th>Person(s) Responsible</th>
<th>When to complete</th>
<th>Where to complete</th>
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<td>3.</td>
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**Predict what will happen when the test is carried out**

| Indicator to measure if prediction succeeds | |
|---------------------------------------------| |


### Implementation Toolkit: Integration of Palliative Care into the PCMH Model

**DO**

<table>
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<tr>
<th>Describe what actually happened when you ran the test.</th>
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</tbody>
</table>

**STUDY**

<table>
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<tr>
<th>Describe the measured results and how they compared to the predictions.</th>
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</table>

**ACT**

<table>
<thead>
<tr>
<th>Describe what modifications to the plan will be made for the next cycle from what you learned.</th>
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<tbody>
<tr>
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