## Rural Community-Based Palliative Care Project

## Measurement Manual for Programs

Winter 2018-2019

## Introduction and Getting Started

The Rural Community-Based Palliative Care Project (2017-2020) is assisting rural communities in North Dakota, Washington, and Wisconsin with establishing and enhancing their communitybased palliative care programs. This manual contains the details, instructions, and links to all data collection materials needed for palliative care programs to participate in project evaluation activities once they begin seeing patients.

Materials can be accessed by visiting www.stratishealth.org/palcare and clicking 'Palliative Care Initiative (login)' in the left sidebar. This page is password-protected to avoid confusion among palliative care programs not participating in this initiative (and not because it contains any confidential information). User name: rural-pc Password: rcpep

## Data collection resources

## - Data Collection Checklist for Programs

Comprehensive list for palliative care programs to get started on data collection activities

- Data Collection Information Form

Form for palliative care programs to complete and send to Stratis Health - contains key data collection and contact details

- Recorded training webinars
- Rural Community-Based Palliative Care Project: Patient-Level Data Collection
- Edmonton Symptom Assessment System (ESAS-r)
- Measurement Manual for Programs (this document)

Manual containing details, instructions, and links to all data collection materials needed for palliative care programs to participate in project evaluation activities once seeing patients.

## - Palliative Care Data Collection Tool

Excel-based data collection tool for entering all palliative care patient data for quarterly submission; also calculates measures for program use (both .xls and .xlsm versions available)

## - Palliative Care Patient Tracker

Optional tool that can help palliative care programs maintain patient confidentiality - patient identifiers cannot be entered into the Palliative Care Data Collection Tool

- Data Dictionary/Specifications Manual

Resource containing data definitions for use with the Palliative Care Data Collection Tool

- Patient Experience Survey

Paper and/or web-based survey to be administered to patients 60 days after initial encounter

- Caregiver Experience Survey

Paper and/or web-based survey to be administered to palliative care family/caregiver 60 days after associated patient's initial encounter

# Data Collection Method: Patient-Level Chart Abstracted <br> Domains: Utilization and Outcomes (plus data elements for monitoring) 

An Excel Palliative Care Data Collection Tool is used to gather information on patient demographics, quality indicators, process measures, and utilization trends. The majority of the information gathered for this tool should be obtained through abstracting electronic health records (or other program documents) and from Edmonton Symptom Assessment Scale-revised (ESAS-r) results.

Data entered in the tool are used to calculate a set of indicators (measures and monitoring results) which are summarized for your use. You will also upload this tool on a quarterly basis to a secure portal (instructions are at the end of this manual).

## Measures captured

## Modified National Quality Forum measures:

- Percentage of palliative care patients screened for pain during the palliative care initial encounter (NQF 1634)
- Percentage of palliative care patients screened for dyspnea during the palliative care initial encounter (NQF 1639)
- Percentage of palliative care patients with documentation in the clinical record of a discussion of spiritual/religious concerns, or documentation that the patient/caregiver did not want to discuss (NQF 1647)
- Percentage of palliative care patients with chart documentation of preferences for life sustaining treatments (NQF 1641)


## Edmonton Symptom Assessment Scale revised (ESAS-r) measures:

- Average first, 30-day, and final ESAS-r score for pain
- Average first, 30-day, and final ESAS-r score for shortness of breath (dyspnea)
- Average first, 30-day, and final ESAS-r score for wellbeing


## Utilization measures:

- Average number of emergency department (ED) visits per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care
- Average number of inpatient stays per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care
- Average length of inpatient stay per patient: both in in the 6 months prior to palliative care, and in the first 60 days of palliative care

Additional data for monitoring palliative care program implementation:
(A full description of each item and elements is in the Data Dictionary/Specifications Manual.)

- Primary referral source to palliative care
- Primary reason for palliative care consult
- Primary patient diagnosis
- Patient residence at time of initial consult
- Reason for discharge from palliative care
- Average length of stay in palliative care
- Patient referrals to resources and services


## Tools you will need

- Palliative Care Patient Tracker (Excel) - optional
- Palliative Care Data Collection Tool (Excel)
- Data Dictionary/Specifications Manual (Excel)
- Your electronic health record (EHR) or equivalent for palliative care program
- Your Edmonton Symptom Assessment Scale-revised (ESAS-r) results


## How to Use the Palliative Care Patient Tracker

To maintain strict patient confidentiality, do not enter any identifying numbers directly linked to the patient into the Patient-Level Data Collection Tool. Examples of identifying numbers directly linked to the patient include Medicare/Medicaid/other insurance numbers, names, or electronic health or medical record identifiers. You must assign a new unique tracking number to each patient to maintain HIPAA compliance.

The Palliative Care Patient Tracker is an optional tool that can help you keep track of the newly assigned unique patient numbers and relationship to each patient. Do not share this patient tracker outside of your program.

## Rural Community-Based Palliative Care Measurement: Palliative Care Patient Tracker

For palliative care internal program use only.
The Medical Record ID number, Patient last name, and Patient first name should all come from the patient's medical record. The Medical Record ID number could also be a Medicare, Medicaid, or other ID, as long as it's a number that allows YOU (the palliative care program) to link a patient to his/her records

The Patient Identifying Number should NOT be related in any way to the patient's record. It should be a completely different number that is only linked to the patient on this Excel sheet. This Patient Identifying Number is what you should use as the patient identifier for the Excel Patient-Level Data Collection Tool, because this is what will be shared with the project evaluator. The Patient Identifying Number is the only number the evaluator should see that is connected to the patient, and should have NO way of linking that number to the actual patient.

| Medical Record ID <br> number (actual) | Patient last name | Patient first name | Patient Identifying Number <br> (assigned) | Initial encounter date | Other notes |
| :--- | :--- | :--- | :--- | :--- | :--- |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
|  |  |  |  |  |  |

# Data Collection Method: Patient Survey and Caregiver Survey 

Domains: Experience/Satisfaction, Outcomes, Utilization

The purpose of the patient and caregiver surveys is to gather information about several domains. These domains, and the surveys that assess them, are:

## Patient and Caregiver Survey:

- Experiences and satisfaction with program
- Patient and caregiver health outcomes


## Patient Survey

- Utilization

While the surveys focus on two of the same domains, the questions within each survey are mostly different. Burden on the person completing the survey was an important consideration in developing the surveys, thus, we tried to minimize the length of both surveys while maximizing the opportunity to collect important feedback from patients and caregivers. Although the caregiver survey is longer, we anticipate that each survey can be completed in approximately 1015 minutes. Results from the surveys will help us to learn more about the ways in which the palliative care programs are influencing the lives of their patients and caregivers.

## Tools you will need

1. Survey Packet:

- Paper surveys and/or links to online version of surveys (if desired)
- Prepaid envelopes self-addressed to Stratis Health
- Large envelope to hold the paper survey and self-addressed envelope to Stratis Health

2. Measurement Manual for Programs (this document)
3. Palliative Care Data Collection Tool (Excel)
4. Palliative Care Patient Tracker (Excel) - optional for tracking surveys administered

## Administration

Administration is similar for both surveys. Patient and caregiver surveys are administered approximately 60 days after the patient's first encounter with the palliative care program. Both surveys are only administered one time during the patient's enrollment. To administer:

1. Assemble separate survey packets for the patient and caregiver surveys. In each packet (inside the large packet envelope), place a copy of the paper survey and a prepaid envelope addressed to Stratis Health (the "packet" envelope just helps to keep the materials organized).
2. Distribute patient and caregiver survey packets at next home or clinic visit.
a. If the caregiver is not present at the next home visit, please leave the packet at the home and call the caregiver to explain the survey. If the caregiver does not live with the patient, mail the survey to the caregiver.
b. If the caregiver is not present at the next clinic visit, mail the survey to the caregiver.
3. Explain a few main points:
a. [For communities offering web versions of the surveys] There is a web version of both surveys available. The web address is included on the front page of each paper survey. The patient and caregiver may complete their respective survey on the web, but please emphasize that they should only complete one version of their survey - either on paper or on the web!
b. The patient should attempt to complete the survey on their own, if possible. If the patient is unable to complete the survey on their own, someone else may help them (though we prefer this is not someone from the palliative care program!).

There are different ways to help the patient complete the survey: 1) by reading the questions and responses verbatim and writing down the patient's answers (this method is preferred, should someone need help); 2) explaining questions and responses as needed to help the patient respond, then writing down the patient's answers; 3) completing the survey without the patient's involvement (if this method is chosen, the survey should be completed on the patient's behalf, and reflecting the perspective of the patient, as much as possible).
c. We prefer that the person who completes the caregiver survey is the patient's main caregiver. If this person is unable to complete the survey, it is permissible for another caregiver to do so.
d. If the patient died before 60 days post-initial encounter, we would still be interested in learning about their experiences with the palliative care program. Please ask the caregiver to complete the survey.
e. Open and honest responses are needed! The completed surveys will be sent directly to Stratis Health, a non-profit organization that supports the palliative care program. Individual responses will not be shared with the palliative care program! Open and honest responses will help Stratis Health and the palliative care program understand what is working well with the program, and what may need to be improved.
f. If a paper survey is completed, place the completed paper survey inside the prepaid envelope addressed to Stratis Health and drop in the mail.
g. Any questions about the survey from the patient or caregiver should be directed to the palliative care program point-of-contact.
4. Update the '60 Day Updates - Survey' section of the Palliative Care Data Collection Tool with the date you administered the surveys (see following pages for instructions).

The surveys are due 2 weeks from the date they were distributed!

## How to Use the Palliative Care Data Collection Tool

## Getting started

Open the Excel data collection tool. Your screen should look similar to the image to the right, which displays the Palliative Care Patient Record List.

You must have macros enabled to use the tool. A macro is a code that runs in the background of the Excel tool. It automates tasks, such as buttons used to
 navigate in the tool. The instructions for how to enable macros will depend on the version of Excel you are using.

## Enabling macros

- If Security Warning appears upon first opening the Excel tool:
- Click on "Options" in the Security Warning at the top of your page
- Click "Enable this content" under Macros
- Ignore the rest of the options and click "OK"
- In Excel 2003:
- In the main toolbar, click on "Tools" and then click on "Options"
- Select "Macros" from this menu, then click "Security" - a new window will appear
- Click on the "Trusted Publishers" tab
- Check the box next to "Trust all installed add-ins and templates" and click "OK"
- In Excel 2007 or 2010:
- Click the Windows symbol at the top left of your toolbar
- Click "Excel Options" at the bottom of the list that appears
- Click "Trust Center" then "Trust Center Settings" then "Macro Settings"
- Select "Disable all macros except digitally signed macros"


## Navigating in the tool

Throughout the tool, buttons should be used for navigation, and boxes shaded light yellow should be used to enter or update data (see screenshot below from the Palliative Care Patient Record List page for an example of buttons and a light yellow box). We do not recommend navigating by clicking on the sheet tabs at the bottom of the Excel tool - use the buttons instead.


## Starting a new record

Enter the name of your community/program in the yellow box on the Palliative Care Patient Record List page, then click the "New Record" button to begin entering data for a new patient. The name of your community/program should be carried over into the first yellow box at the top of the Palliative Care Patient Data Entry Form. Begin entering data in the subsequent yellow boxes. Note that many yellow boxes include dropdown menus with options to choose from (view the Data Dictionary for details on what each dropdown menu includes).


If you wish to cancel data entry, clicking the "Cancel" button will prompt a pop-up box to appear. Click "Yes" if you truly wish to cancel data entry without saving (and return to the Palliative Care Patient Record List page). Click "No" if you wish to remain on the Palliative Care
 Patient Data Entry Form and keep entering data.

At any point, click the "Save/Update Record" button to save your entered data. You must click this button for any of your data to be saved! Upon clicking the button, you will see one of two pop-up boxes:

The message to the right will appear if you are entering a new palliative care patient's data for the first time. Click "Yes" if you wish to save the data you have


Microsoft Excel


This will overwrite existing record. Are you sure?

## Yes

No

The message to the left will appear if you have already entered and saved data for a patient and are updating any of the data for that patient. Clicking "No" will cancel any updates made for that patient record (but any alreadyexisting data will be retained). Clicking "Yes" will update that patient's data. Note that if you have changed any existing data for a patient, that data will be overwritten by the updates you have made. If you have simply added new data for a patient (but did not change anything you had already entered) then the existing data will be retained and any of the new data will also be saved for that patient.

Once you have saved (or updated) a Palliative Care Patient Data Entry Form, you will be returned to the Palliative Care Patient Record List page. If you have entered a new record you should notice that this record now appears on the Palliative Care Patient Record List.

## StratisHealth <br> Palliative Care Patient Record List



## Updating records

From the Palliative Care Patient Record List page, you can:

- Open a record: Do this if you wish to review data entered for any patient in more detail, make changes to data that has already been entered, or enter new data after you have entered data for the initial encounter. Click on the appropriate row and click "Open Record" in order to open an existing record. If you click "Open Record" from a blank row you will be asked if you wish to create a new record instead.
- Delete a record: If you entered a patient record in error, you must use this button to remove it. To delete a record, click on the appropriate row and click "Delete Record." You will receive a prompt asking if you are certain you wish to delete the record - click "Yes" only if you are certain it should be deleted, as this is a permanent deletion and it cannot be undone.


## Viewing reports

From the Palliative Care Patient Record List page, you can navigate to two different reports: the Measure Report, and the Monitoring Report.


The "View Measure Report" button will take you to a quarterly summary report that displays your palliative care program's performance on modified NQF, ESAS-r, and utilization measures (described in previous pages).


The "View Monitoring Report" button displays a quarterly summary report that provides some descriptive monitoring/process data that may be helpful to your program (also described on previous pages).


On both reports, simply update the Year of Report in the light yellow box to summarize a different year. Click the "Record List" button to navigate back to the Palliative Care Patient Record List.

## Guidance for data collection and entry

The Data Entry Form within the patient-level data collection tool is divided into the following six sections:

## 1. Initial Data Collection Information

2. Utilization - Chart Review ( 6 month lookback) - if able to obtain (see Data Dictionary/Specifications Manual for details)
Complete these two sections following the patient's initial encounter.

## 3. 30 Day Updates

Complete this section after 30 days have passed from the initial encounter, as long as the patient is still enrolled in your palliative care program.
4. 60 Day Updates - Survey

Patient surveys and caregiver surveys should be administered after 60 days have passed from the initial encounter. These details are captured in this section of the tool.
5. Utilization - Chart Review (patient's first 60 days on palliative care) - if able to obtain (see Data Dictionary/Specifications Manual for details)
Complete this section after 60 days have passed from the initial encounter as long as the patient is still enrolled in your palliative care program.
6. Patient Discharge Details

Once the patient has been discharged from your palliative care program, update this section.
7. Final Updates (lookback after patient was discharged)

Once the patient has been discharged from your palliative care program, complete this section. If the patient has a short tenure (less than 30 days) on palliative care, this section should be updated instead of the 30 Day Update.

## Data submission setup and process

Each palliative care program will be provided with an account login and password to a secure site for data submission, which is managed through a NORC Secure FTP site.

Once your program's account is available, follow the Secure FTP manual instructions at the very end of this Measurement Manual to complete setup. Contact Laura for assistance if needed.

## To submit your data:

1. Log in to your Secure FTP site using instructions in Appendix, at the end of this Measurement Manual.
2. Make a copy of your program's Palliative Care Data Collection Tool. Rename the copy to include the quarter of data submission at the end of the name. For example, when submitting Quarter 12019 data, rename the tool so that it ends in "2019Q1" or similar.
3. Click and drag this file into your Secure FTP site window (again follow instructions in Appendix at the end of this Measurement Manual).

## Data submission schedule

We recognize that programs will vary on enrolling patients and the ability to collect data. Once you begin submitting data, the submission timeline below should be used.

| For patient initial palliative care encounter dates | Note | Submit data by |
| :---: | :---: | :---: |
| Prior to January 1, 2019 | Also update records as appropriate for the 30-day encounter, 60-day survey and utilization, discharge, and final update | TBD - contact Laura |
| January 1-March 31, 2019 (Q1 2019) |  | April 30, 2019 |
| April 1 - June 30, 2019 (Q2 2019) |  | July 31, 2019 |
| July 1 - September 30, 2019 (Q3 2019) |  | October 31, 2019 |
| October 1 - December 31, 2019 (Q4 2019) |  | January 31, 2020 |
| January 1-March 31, 2020 (Q1 2020) |  | April 30, 2020 |
| April 1 - June 30, 2020 (Q2 2020) |  | July 31, 2020 |

## Need Assistance?

## Contact:

Laura Grangaard Johnson, Senior Research Analyst, Stratis Health
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Phone: 952-853-8544

## Rural Community-Based Palliative Care Project Evaluation Measures

| Required or Optional | Measure <br>  <br> Topic | Measure or Monitoring Element Description | Data Source | Data Collection Method |
| :---: | :---: | :---: | :---: | :---: |
| Required | Clinical | Percentage of palliative care patients screened for pain during the palliative care initial encounter (NQF 1634) | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Clinical | Percentage of palliative care patients screened for dyspnea during the palliative care initial encounter (NQF 1639) | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Clinical | Percentage of palliative care patients with documentation in the clinical record of a discussion of spiritual/religious concerns, or documentation that the patient/caregiver did not want to discuss (NQF 1647) | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Clinical | Percentage of palliative care patients with chart documentation of preferences for life sustaining treatments (NQF 1641) | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Clinical | Average first, 30-day, and final ESAS-r score for pain | ESAS-r | Palliative Care Data Collection Tool |
| Required | Clinical | Average first, 30-day, and final ESAS-r score for shortness of breath | ESAS-r | Palliative Care Data Collection Tool |
| Required | Clinical | Average first, 30-day, and final ESAS-r score for wellbeing | ESAS-r | Palliative Care Data Collection Tool |
| Optional (depending on program access to this) | Utilization | Average number of ED visits per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care | EHR or other program documentation | Palliative Care Data Collection Tool |
| Optional (depending on program access to this) | Utilization | Average number of inpatient stays per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care | EHR or other program documentation | Palliative Care Data Collection Tool |
| Optional (depending on program access to this) | Utilization | Average length of inpatient stay per patient: both in the 6 months prior to palliative care, and in the first 60 days of palliative care | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Operational <br> (Monitoring) | Primary referral source to palliative care | EHR or other program documentation | Palliative Care Data Collection Tool |


| Required or Optional | Measure <br>  <br> Topic | Measure or Monitoring Element Description | Data Source | Data Collection Method |
| :---: | :---: | :---: | :---: | :---: |
| Required | Operational <br> (Monitoring) | Primary reason for palliative care consult | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Operational <br> (Monitoring) | Primary patient diagnosis | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Operational <br> (Monitoring) | Patient residence at time of initial consult | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Operational (Monitoring) | Reason for discharge from palliative care | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Operational <br> (Monitoring) | Average length of stay in palliative care | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Operational <br> (Monitoring) | Patient referrals to resources and services | EHR or other program documentation | Palliative Care Data Collection Tool |
| Required | Patient <br> Experience | Palliative care patients reporting satisfaction with palliative care experience after 60 days | Survey | Patient <br> Experience Survey |
| Required | Caregiver Experience | Palliative care family/caregivers reporting satisfaction with palliative care experience after 60 days | Survey | Caregiver <br> Experience Survey |
| Optional | Patient <br> Experience | Palliative care patients' selfreported perception of health | TBD | TBD |
| Required | Community Capacity | Details of staff and program attributes | Palliative care team discussion | Program Operations survey |
| Required | Community Capacity | Details of resources, needs, and opportunities in community with respect to palliative care | Palliative care team discussion (pre \& post) | Asset \& Gap Analysis form |
| Subset of programs will participate | All | Qualitative details of programs | Discussion with evaluators | Interviews \& Site Visits |

## Appendix: NORC Secure FTP Manual

## What is a SFTP Client?

SFTP, or secure FTP, is a program that uses SSH to transfer files. Unlike standard FTP, it encrypts both commands and data, preventing passwords and sensitive information from being transmitted in the clear over the network. It is functionally similar to FTP, but because it uses a different protocol, you can't use a standard FTP client to talk to an SFTP server, nor can you connect to an FTP server with a client that supports only SFTP.

There are two ways you can use SFTP: graphical SFTP clients and command line SFTP.
Using graphical SFTP clients simplifies file transfers by allowing you to transmit files simply by dragging and dropping icons between windows. When you open the program, you will have to enter the name of the host (e.g., sftp.norc.org) and your username and password. An example of the two-pane window is below:


Users can install the ftp client software from http://winscp.net/eng/index.php. (When installing the software please choose all of the default settings).

Once installed the initial login screen is shown below.

## SFTP Login Screen



## Login information

The hostname name is sftp.norc.org

## Internal Users

- Username: lastname-firstname Password: Your network password


## External Users

- Username and password will be given to you.


Do not enter any information for the Private Key File.

Once you click on "Login" you will see the message below.
Please click "Yes" to it.


You will then see the "Authentication Banner". Please click the "continue" button to complete the login.


Once the login is complete you will see the screen below. If you are using WinSCP for the first time, you may want to start with the Explorer-like interface. You can select the interface during installation.

You can drag files to and from this window, other Explorer windows, and your desktop. To access additional operations, right-click any object, and then select the operation from the context menu. You can also right-click a file or a directory, and then drag it to another location.


To logout of the session go to the Commands Menu and click "F10" on your keyboard.


