**Rural Community-Based Palliative Care Project**  
**Data Collection Checklist for Programs**

All materials are posted to [www.stratishealth.org/palcare](http://www.stratishealth.org/palcare)  
**User name:** rural-pc  
**Password:** rcpc

### Get up to speed

- **Identify a program person as the data lead**
  - Multiple team members can collect data, but all communication to and from Stratis Health regarding data will flow through the data lead.

- **Read Measurement Manual for Programs**

- **Attend and/or listen to training webinars:**
  - *Rural Community-Based Palliative Care Project: Patient-Level Data Collection* (January 28, 2019) – include data lead at minimum
  - *Edmonton Symptom Assessment System* (ESAS-r) webinar with all key team members (December 11, 2018) – include all key team members

- **Ensure process for capturing ESAS-r data** (link: [http://www.palliative.org/NewPC/professionals/tools/esas.html](http://www.palliative.org/NewPC/professionals/tools/esas.html))

### Get processes in place

- **Identify roles & responsibilities for collecting and submitting evaluation data**
  - Revisit Measurement Manual for Programs and review Data Collection Information Form to understand components

- **Decide how you will track patients to avoid submission of personal health information (PHI) or personal identifying information (PII)**
  - Consider using Palliative Care Patient Tracker

- **Decide on Patient survey and Caregiver survey processes** (revisit Data Collection Information Form for more information), including:
  - Paper vs Web, and distribution processes

- **Complete Data Collection Information Form** and send to Stratis Health

- **Send a logo (if available) for your community Palliative Care program**, and Stratis Health will add it to surveys

### Get ready to collect data

- **Download Palliative Care Data Collection Tool**

- **Read supplemental materials** (ensure this is complete before entering any data)
  - Data Dictionary/Specifications Manual
  - Survey protocols/questions
Ensure you have received initial surveys/pre-paid envelopes and/or link to survey for patient and caregiver/family

Complete setup of NORC Secure FTP site
- Measurement Manual for Programs contains instructions, Data Collection Information Form has setup details. Laura initiates setup, but your program must complete

Determine need or desire for Data Use Agreement (DUA)

Ongoing
- Request more pre-paid envelopes as needed from Laura (contact information below)
- Keep up-to-date on data collection and entry, including administering surveys to patients and caregivers 60 days after initial encounter
- Submit palliative care data according to data submission timeline (below)
- Revisit recorded trainings as needed
- Send questions or requests for assistance to Laura
- Alert Laura if data lead changes or if any issues arise in submitting data

Stratis Health commitments
- Provide technical assistance for data collection, submission, and measurement questions
- Initiate setup of NORC Secure FTP site for community program (based on information supplied in Data Collection Information Form)
- Provide pre-paid envelopes and paper surveys, and/or online survey link, for patient surveys and caregiver surveys. If communities choose, will personalize with logo.
- Send data submission reminders to data lead, both 1 month and 1 week in advance
- Provide summary and comparison data (details TBD)

Communication
Laura Grangaard Johnson, Senior Research Analyst at Stratis Health, will serve as conduit for communication and questions. Communication to your community program will primarily be via email, but do not hesitate to pick up the phone. Your program’s data lead will always be included on the email and your State Office of Rural Health will be copied on all communication as well. The data lead is responsible for bringing others in your program into the conversation if needed.

Email: lgrangaard@stratishealth.org Phone: 952-853-8544

Data Submission Schedule
Once you begin submitting data, the timeline below should be used.

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