

## Palliative Care Data Collection On-line Survey – Instructions

Go to the following web-site for all data entry, updates and submissions:

[http://dev.dreamcreative.com/palliativecare/admin\\_patient\\_list.aspx](http://dev.dreamcreative.com/palliativecare/admin_patient_list.aspx)

### Getting Started:

1. Log on using assigned **User Name** and **Password**.
2. The first screen to appear is the **Main Menu**, which contains the following options: **Patient Manager**, **System Tools** and **Log Off**.

### Patient Manager:

1. To enter a new patient, select the **Patient Manager** option.
2. A **Patient List** will appear.
3. Click either **Add Inpatient** or **Add Outpatient** depending on the type of patient being consulted.
4. All appropriate spaces or circles for every patient must be completed.
5. A minimum amount of information will be required to get a record “started”. Even if you plan to come back later to finish the record, the following fields are required during your first entry: **ID, date of birth, gender, county, admission date and referral date**. These variables are noted by an \* in the record. (See *Partial Completion, page 4*).
6. See **Record Definitions** below to help with record completion.

**NOTE: The Patient ID is a computer-generated number used for sorting the database of records. (See Filtering Data Section, page 5).**

### Inpatient Record Definitions (See page 9 for Outpatient Instructions)

*If the wrong option is accidentally chosen (Example: Divorced picked, when it should have been Married) just click the correct choice and the selection will change. This is the case for all variables.*

**IMPORTANT\*\*\* Please keep a personal log record of the assigned Patient ID and which patient the Patient ID corresponds. This will be used for future data filtering and any needed database corrections. Example: Patient ID 12345, SSN# 1234.**

#### Demographic Data:

Record all the basic information about the person. Be sure and include county of residence, meaning where the person lives, not the location of the facility.

#### Pediatric Service:

Fill in the bubble for Pediatric Service when you are consulted for a patient that is deemed pediatric. Pediatric is defined as 21 years of age or younger regardless of disease.

**Date of Admission:**

Enter all months and days as two digits and all years as four digits. All dashes have been included for convenience.

***Example: March 3, 2014 will be 03-03-2014.***

Complete the date of admission and select if the patient was admitted to the hospital, nursing home/SNF, ICU/Stepdown, SNU or ED.

Mark the location of where the consult occurred: Hospital Floor Bed, ED, ICU/Stepdown, Nursing Home/SNF, SNU, OB L&D, NICU, PICU or Peds Floor.

**Date of referral:**

Enter all months and days as two digits and all years as four digits. This is the date palliative care was consulted.

***Example: March 3, 2014 will be 03-03-2014.***

**Initial Reason for Consult:**

Mark only one – the primary reason for the consult. You may not always know why but try to find out from Palliative Care or from the chart.

**Primary Diagnosis for Consult:**

Select only one of the major life-threatening illnesses. This will be the diagnosis that Palliative Care was been consulted for, NOT the admitting diagnosis.

**Multiple chronic illnesses:**

If the patient has multiple chronic illnesses mark **yes**, if not, mark **no**. If **yes**, was the number  $\leq 2$  or  $> 2$ .

**PPS:**

This is the palliative performance scale (see page 8). Many of the patients will be less than 50%.

**Would you be surprised if the patient died in the next year?**

This assessment is by Palliative Care.

**Decision Making Capacity:**

Mark whether or not the patient had decision-making capacity at time of first visit, or if you are unable to determine. If a patient **DOES NOT** have decision capacity, the MPOA and Living Will **CAN NOT** be initiated by Palliative Care. If patient regains capacity and you help them complete and advance directive update the form to show that MPOA or Living Will was initiated by Palliative Care.

**Inappropriate coping or anticipatory grief:**

**Coping mechanisms** are ways of behavior to cope with the difficulties and stress. Abnormal coping might include denial, acting out, aggression, drugs or alcohol use, emotional outburst, or avoidance.

**Anticipatory grief** helps to prepare for the impending death. However, the grief should not overwhelm and incapacitate the family/support person to the point that they are not able to meet the needs of themselves (not eating or sleeping) or the needs of the patient.

**Symptoms at initial assessment:**

Palliative Care should mark symptoms and evaluate symptom control with each contact. The symptoms are determined by the patient's self-report or by observation.

**Symptom Definitions:**

**Delirium** is a sudden, severe, and fluctuating change in mental status including difficulty maintaining attention, disorientation, hallucinations, fluctuating levels of consciousness, and rapid changes in mental status from confusion to lethargy to agitation.

**Confusion** is the inability to think with your usual speed or clarity, including feeling disoriented and having difficulty paying attention, remembering, and making decisions.

**Initial, 24 hour, 48 hour Pain Assessment Scale Used:** Select the appropriate scale used to assess pain.

**Initial, 24 hour, 48 hour Pain Assessment:**

**Collect data only if initial visit was on a Monday, Tuesday, or Wednesday OR on days when a 24 or 48-hour follow-up could be done.**

**DNR:**

You are required to select either the **yes** or **no** option for this section. An error message will appear if the variable has not been completed.

If the patient has a DNR order, mark **yes**. If not, mark **no**. If you initiate a DNR order during that specific admission, fill in the appropriate choice of yes.

**DNR Card:**

You are required to select either the **yes** or **no** option for this section. An error message will appear if the variable has not been completed.

If the patient has a DNR Card, mark **yes**. If not, mark **no**. If you initiate a DNR Card, fill in the appropriate choice of yes.

**Advance directives:**

You are required to select either the **yes** or **no** option for this section. An error message will appear if these variables have not been completed.

If the patient already had advance directives, mark **yes**. If not, mark **no**. If you initiate a living will, MPOA, health care surrogate or legal guardian during the current consult be sure to mark **yes** where indicated. Those patients without decision capacity **CAN NOT** have an MPOA or living will initiated by Palliative Care.

If a POST form was completed be sure to mark **yes**. If not, mark **no**. Respond if the POST form was completed by Palliative Care. If a patient already has a POST form before admission mark "Yes", but "No" for initiated. If POST Form is changed during consult mark "Yes" for initiated.

**Treatments in use and changes while PCT involved in care:**

The "In Use" box should be selected regardless of when the treatment was started; either prior to or during the palliative care consult. If treatment was in use and stopped, select Stopped from the drop down box. If no treatments were currently being used DO NOT mark the "In Use" box. If a treatment was Avoided, select Avoided from the drop down box, the "In Use" box will be blank.

**Surgery or invasive procedures**

Invasive procedures enter the body, usually by cutting or puncturing the skin or by inserting instruments into the body; these include chest tubes, central lines, NG tubes, feeding tubes, paracentesis, thoracentesis or bronchoscopy.

**Interventions by PCT:**

Select **all** (fill in circles) of the interventions that apply.

**Outcomes or decisions followed by family:**

Select **all** (fill in circles) that apply.

**Date of discharge:**

This is the date palliative care has stopped following the patient.

***Example: March 3, 2014 will be 03-03-2014.***

**Disposition: (mark only one)**

Why was the patient discharged? Did the patient die or was he/she discharged to another facility? If you follow the patient to SNU, SNF, or home complete the date of death and place of death if applicable.

Note the following definitions for disposition: **Hospital (Transfer)** – patient is transferred to a facility other than where the person is currently a patient, **LTAC** – Long Term Acute Care Facility, **PCU** – Progressive Care Unit, **Team services no longer needed** – Patient is requesting aggressive treatment, **Outpatient**

**Palliative Care Team** – use this option when the patient was discharged from the hospital to an “outpatient palliative care team”.

**Date of death:**

**Answer this question ONLY if the disposition marked is death.** This date could be the exact date of discharge, please complete both variables. This date could also be after the discharge date, but still needs to be completed.

***Example: March 3, 2014 will be 03-03-2014.***

**Record Completion:**

There are two types of record completion -- partial completion and final completion. Either way the record **MUST** be **SUBMITTED** prior to leaving the Data Entry Screen.

**Always select the SUBMIT button at the bottom of the screen. Data will be lost if this step is not completed.**

**Partial Completion:**

1. A minimum amount of information will be required to get a record “started”. The following fields will be required during your first entry: **ID, date of birth, gender, county, admission date and referral date**. These variables are noted by an \* in the record.
2. You can partially complete a record and come back to it later, but again you **MUST** hit the SUBMIT button before leaving the Data Entry Screen. **If you don't do this, the record will be LOST and you'll have to start all over.** Once you SUBMIT the record you'll be taken back to the Patient List Screen. **You'll need to record the assigned Patient ID in a log that matches a patient identifier. This will be for your personal use and future data filtering. (See Filtering Data Section, page 5).**

**Final Completion:**

1. Once ALL fields are complete you will need to check the box at the very bottom of the Data Entry Screen that says, “**Check here to indicate this record is complete**”, and then hit Submit. Once again, a Patient\_ID will be assigned and viewable on the Patient List, keep it for future reference.
2. A system has been put in place to double check all questions for completion. If certain questions are missing an error message will appear after the Submit button is hit. Those variables will need to be completed before you will be able to officially submit the data.
3. If you do not wish to keep any of the entered data for the current record scroll to the top of the entry screen and hit MAIN MENU and you will be returned to the Patient List screen.

## **Printing Records:**

If you want to keep a hard copy of the on-line records you can do so directly from the record. First open the record you wish to print, go to File and select Print.

## **Filtering Data:**

Data can be filtered several different ways by using the **Patient List** screen. The **Patient List** screen is set up strictly for record sorting and retrieval.

1. The Search box on the **Patient List** screen can be used for data sorting. Example: Enter in the Patient\_ID for the patient you wish to view, update or complete and the records will automatically sort to show that record. The data will sort to show this patient first, click on Edit to retrieve the record.
2. If you didn't record the Patient\_ID during your initial entry you will still be able to sort using one of the title variables, Time Stamp, Date of Birth, etc. Enter in the information in the Search box and the matching record will appear first.
3. Data can also be sorted by clicking on the title fields. One click allows the data to be sorted ascending and clicking again will sort the data descending.
4. Use the boxes on the bottom right side of the screen to go from page to page as only a limited number of records will appear at one time on the **Patient List** screen.
5. If after Filtering you want to see your entire patient list, erase the information from the Search box. Your complete list of patients will return to the screen.

You will use this process for ALL record Updating, *see below*.

## **Updating Data:**

If you have returned to the system to update a record you will need to do the following:

1. Chose the unique identifier (Patient\_ID) for that particular record and enter it into the Search box on the **Patient List** screen.
2. Once the right record is located click on Edit.
3. Enter all the appropriate updates.
4. Scroll to the bottom of the Entry Screen and select Submit or page back and no changes will be submitted.

## **Documents:**

Please note the posted documents:

1. Instruction Manual - A copy of the Instruction Manual will be accessible here. Please review the manual regularly, as changes might have occurred.
2. Contact List - Questions, concerns, or suggestions, note contacts. Also included is a list of all Palliative Care Coordinators.

3. Paper Form - A hard copy of the actual survey will be posted for those individuals who would like to continue to collect data manually prior to entering information directly on-line. This should be used only a template for easier data collection.

### **Download Facility Report:**

On the **Main Menu** select **Download Facility Report**.

Two options will appear.

1. "Open with." There is a Browse Button to select the file to be opened with Excel.  
This option will open the downloaded data as a .csv file. It will appear to be in an Excel Spreadsheet, but once the file is open, re-save it as an Excel (.xls) file to a specific folder.
2. "Save."  
Select a folder in which to save the file. **Do not** change the file extension. Leave it as a .csv file and click Save. A Download Complete box will appear with 3 options:
  - Open** – File will open as a .csv. Re-save as an Excel (.xls) file.
  - Open Folder** – The folder in which the file was saved will open. File can then be opened and re-saved as Excel (.xls).
  - Close** – The Download box will close. The file can then be accessed by searching for the folder in which it was saved. File can then be opened and re-saved as an Excel (.xls) file.

Once data is successfully downloaded it can be analyzed in Excel.

### **Log Off:**

**Remember to click the Submit Button before logging out. Data will be lost if this final step is not completed. Log out of the system.**

## PALLIATIVE PERFORMANCE SCALE

<b>%</b>	<b>Ambulation</b>	<b>Activity and Evidence of Disease</b>	<b>Self-Care</b>	<b>Intake</b>	<b>Conscious Level</b>
100	Full	Normal activity	Full	Normal	Full
90	Full	No evidence of disease	Full	Normal	Full
80	Full	Normal – some evidence of disease	Full	Normal or Reduced	Full
70	Reduced	Unable normal job/work some evidence of disease	Full	Normal or Reduced	Full or Confusion
60	Reduced	Unable hobby, housework. Significant disease	Occasional assistance necessary	Normal or Reduced	Full or Confusion
50	Mainly sit/lie	Unable to do any work. Extensive disease	Considerable assistance required	Normal or Reduced	Full or Confusion
40	Mainly in bed	As above	Mainly assistance	As above	Full or drowsy or confusion
30	Totally bed bound	As above	Total care	Reduced	As above
20	As above	As above	Total care	Minimal sips	As above
10	As above	As above	Total care	Mouth care only	Drowsy or coma
0	Death				

Ref: Anderson, Downing, Hill, “Palliative Performance Scale: A new tool”, Journal of Palliative Care 1996 12:1; 5-11.

The PPS is a modified Karnofsky Performance Scale which does not depend on location of care to predict prognosis and more accurately reflects physical decline. Judgement is required if one of the five factors observed does not fit with the other.



## Outpatient Record Definitions

*If the wrong option is accidentally chosen (Example: Divorced picked, when it should have been Married) just click the correct choice and the selection will change. This is the case for all variables.*

**IMPORTANT\*\*\*** Please keep a personal log record of the assigned Patient ID and which patient the Patient ID corresponds. This will be used for future data filtering and any needed database corrections. Example: Patient ID 12345, SSN# 1234.

### **Demographic Data:**

Record all the basic information about the person. Be sure and include county of residence, meaning where the person lives, not the location of the facility.

### **Pediatric Service:**

Fill in the bubble for Pediatric Service when you are consulted for a patient that is deemed pediatric. Pediatric is defined as 21 years of age or younger regardless of disease.

### **Date Seen:**

Enter all months and days as two digits and all years as four digits. All dashes have been included for convenience.

**Example: March 3, 2014 will be 03-03-2014.**

Complete the date seen and select if the patient was seen in Home, Nursing home/SNF, Personal Care Home or Assisted Living Facility.

If the patient was seen in an office type in the facilities name in the box provided. Please try to stay consistent with your office names.

**Example: March 3, 2014 will be 03-03-2014.**

### **Initial Reason for Consult:**

Mark only one – the primary reason for the consult.

### **Primary Diagnosis for Consult:**

Select only one of the major life-threatening illnesses. This will be the diagnosis that Palliative Care was consulted for, NOT the admitting diagnosis.

### **Multiple chronic illnesses:**

If the patient has multiple chronic illnesses mark **yes**, if not, mark **no**. If **yes**, was the number  $\leq 2$  or  $> 2$ .

### **PPS:**

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**Would you be surprised if the patient died in the next year?**

This assessment is by the Palliative Care.

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**Symptom Definitions:**

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**Confusion** is the inability to think with your usual speed or clarity, including feeling disoriented and having difficulty paying attention, remembering, and making decisions.

**Pain Assessment Scale Used:** Select the appropriate scale used to assess pain.

**Pain Assessment Date:** There are spaces for up to three different dates of pain assessment.

**DNR:**

You are required to select either the **yes** or **no** option for this section. An error message will appear if the variable has not been completed.

If the patient has a DNR order, mark **yes**. If not, mark **no**. If you initiate a DNR order during that specific visit, fill in the appropriate choice of yes.

**DNR Card:**

You are required to select either the **yes** or **no** option for this section. An error message will appear if the variable has not been completed.

If the patient has a DNR Card, mark **yes**. If not, mark **no**. If you initiate a DNR Card, fill in the appropriate choice of yes.

**Advance directives:**

Mark whether the Living Will, MPOA, HCS or POST form was **discussed** or **completed** during the visit. If the patient already had advance directives, mark **completed**. Those patients without decision capacity **CAN NOT** have an MPOA or living will initiated by Palliative Care.

**Treatments in use and changes while PCT involved in care:**

The “In Use” box should be selected regardless of when the treatment was started; either prior to or during the palliative care consult. If treatment was in use and stopped, select Stopped from the drop down box. If no treatments were currently being used DO NOT mark the “In Use” box. If a treatment was Avoided, select Avoided from the drop down box, the “In Use” box will be blank.

**Interventions by PCT:**

Select **all** (fill in circles) of the interventions that apply.

**Outcomes or decisions followed by family:**

Select **all** (fill in circles) that apply.

**Final Completion:**

1. Once ALL fields are complete you will need to check the box at the very bottom of the Data Entry Screen that says, “**Check here to indicate this record is complete**”, and then hit Submit. Once again, a Patient\_ID will be assigned and viewable on the Patient List, keep it for future reference.
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