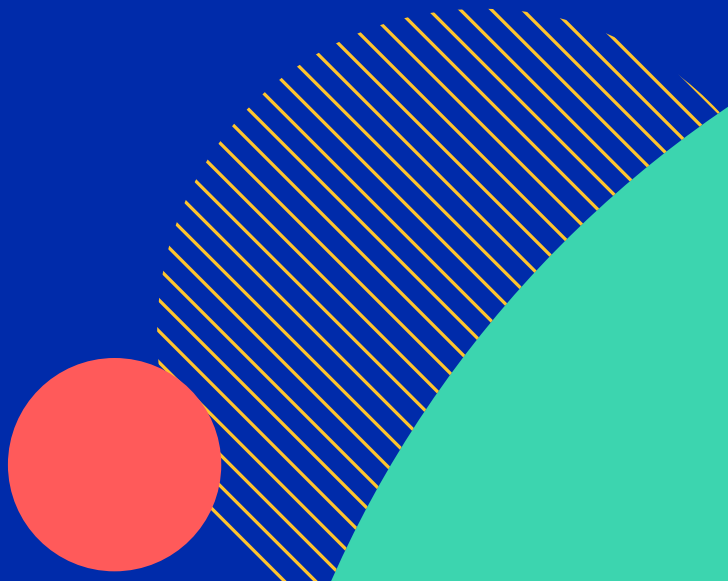
HIMSS

Creation of a Novel Pediatric Palliative Care Navigator

to Improve End-of-Life Care for Children with Serious Illness



DAVIES
AWARD OF EXCELLENCE

Creation of a Novel Pediatric Palliative Care Navigator to Improve End-of-Life Care for Children with Serious Illness

Executive Summary

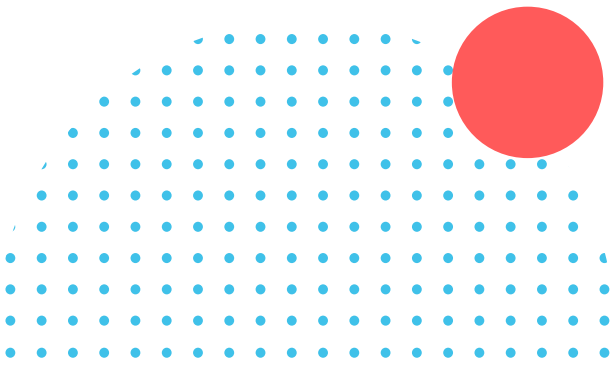
Pediatric end of life care is starkly different compared to adults. There are no benchmark quality metrics in pediatric palliative care, advance care planning conversations are poorly documented and there are no pediatric-specific electronic health record navigators to guide standard of care. This leads to suboptimal care at the end of a child's life. An interdisciplinary group of three nurses and two physicians with quality and information technology experience developed the first comprehensive and interdisciplinary pediatric palliative navigator to help tailor pediatric needs, drive development of benchmarks in our field, and ensure gold standard, quality and equitable care delivery to children dying of serious illness.

The navigator includes custom pediatric end of life topics, order sets, templated notes using SmartData elements, checklists and risk scales, clinician order specific prompts with order signing, flowsheet based SmartForms, hyperlinks, and more. Primary process changes that drove improvements in our outcomes include carrying out focus groups with key stakeholders to assess needs and using quality improvement science for rapid cycle implementation. After implementation, advance care planning documentation improved by 35%, deaths were attended by interdisciplinary team members 80% of the time (increased from 50%), post-mortem paperwork became electronic, and quality metrics were developed and collected electronically. This led to Epic writing the first clinical program of its kind, The Joint Commission Certification in Advanced Palliative Care and federal funding awards.

Critical elements and lessons learned for success include ensuring nursing leadership collaboration because nurses are essential users. While nurses received extensive training as part of their quarterly training track, at-the-elbow support was essential at go-live, particularly in areas where pediatric deaths are less common (outside of the intensive care unit). Rounding with users was helpful to get them comfortable with the new workflow and allowed for feedback for rapid cycle changes. Partnering with pathology was essential, as they had a different workflow. These critical elements impacted nursing training modules and physician education throughout the institution.

The Clinical Problem and Pre-implementation Performance

In order to provide gold standard patient and family centered care, discussions regarding goals of care and advance care planning are essential for patients and families with life-limiting illnesses. There are many elements that need to be considered when caring for chronically or terminally ill patients. Some of these elements include conversations surrounding code status, pain and symptom management, limitations of interventions, organ donation status, autopsy requests and bereavement support. These topics are often difficult to initiate, particularly in pediatrics. In addition, because the trajectories of life-limiting illnesses in pediatrics often take on a prolonged sinusoidal curve with a general decline over time, goals and priorities for care may change frequently.



As of 2018, a new law (Texas Senate Bill 11) was enacted, requiring documentation of code status conversations in the inpatient medical record for any code status other than "Full Code." Prior to this law, only 60% of code orders were changed with corresponding documentation or communication to incoming team members. Since there was little to nothing documented, parents were often being asked to have the same conversation repeatedly over the same admission and either starting to doubt their decisions or sensing the lack of communication taking place when teams changed. Thus, there was a crucial need to readily access goals of care and advance directives for these patients.

As a new sub-specialty in pediatrics, there are no national benchmarking metrics for inpatient pediatric palliative care. We have adapted adult palliative metrics from The Joint Commission and the federal Delivery Incentive Reform Program (DSRIP) to demonstrate gold standard care in pediatrics.

The metrics for Joint Commission (data steward for these metrics) certification include the following:

1. Screening for pain – Numerator: patients with recorded pain screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: use of neuromuscular blocking agents. Pre-implementation data show baseline median for this metric was 86%. The targeted performance goal was based on continued improvement from baseline.

2. Screening for dyspnea – Numerator: patients with recorded pain screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: use of neuromuscular blocking agents. Pre-implementation data show baseline median for this metric was 56%. The targeted performance goal was based on continued improvement from baseline.

3. Performing a pain assessment when pain is reported – Numerator: patients with five descriptors of pain assessment. Denominator: patients reporting presence of pain. Exclusion criteria: use of neuromuscular blocking agents. Pre-implementation data show baseline median for this metric was 38%. The targeted performance goal was based on continued improvement from baseline.

4. Documenting treatment preferences – Numerator: patients with recorded treatment preferences. Denominator: patients receiving a palliative care consult. Exclusion criteria: none. Pre-implementation data show baseline median for this metric was 100%. The targeted performance goal was based on maintained improvement.

5. Communicating the treatment preferences to the referring pediatrician – Numerator: patients with a letter sent to pediatrician reporting treatment preferences and palliative care involvement. Denominator: any palliative care patient who was discharged alive from the hospital. Exclusion criteria: inpatient death or signed off of palliative care service. Pre-implementation data show baseline median for this metric was 9%. The targeted performance goal was based on continued improvement from baseline.

DSRIP metrics include the following. Texas Health and Human Services Commission (HHSC) is the data steward for these metrics. Pre-implementation data was collected by manual chart review:

6. Pain assessment at initial consult when pain is reported as >4/10 – Numerator: patients with five descriptors of pain documented. Denominator: patients reporting >4/10 pain on initial consult. Exclusion criteria: use of neuromuscular blocking agents, admission to palliative care <24h prior to discharge, or prior palliative care consult. Pre-implementation data show baseline median for this metric was 42%. The targeted performance goal was an increase of 2.5% by performance year one and a 10% increase from baseline in performance year two.

7. Dyspnea screen at initial consult – Numerator: patients with recorded dyspnea screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: use of neuromuscular blocking agents, admission to palliative care <24h prior to discharge, or prior palliative care consult. Pre-implementation data show baseline median for this metric was 54%. The targeted performance goal was an increase of 2.5% by performance year one and a 10% increase from baseline in performance year two.

8. Dyspnea treatment when dyspnea is identified at initial consult – Numerator: patients with recorded dyspnea treatment. Denominator: patients reporting dyspnea on initial palliative care consult. Exclusion criteria: use of neuromuscular blocking agents, admission to palliative care <24h prior to discharge, or prior palliative care consult. Pre-implementation data show baseline median for this metric was 31%. The targeted performance goal was an increase of 2.5% by performance year one and a 10% increase from baseline in performance year two.

9. Documentation of spiritual beliefs and values – Numerator: patients with recorded spiritual screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: 17 years of age or younger, admission to palliative care <24h prior to discharge, or prior palliative care consult. Pre-implementation data show baseline median for this metric was 71%. The targeted performance goal was an increase of 2.5% by performance year 1 and a 10% increase from baseline in performance year 2.

10. Identification of treatment preferences – Numerator: patients with recorded treatment preferences. Denominator: patients receiving a palliative care consult. Exclusion criteria: Admission to palliative care <24h prior to discharge or prior palliative care consult. Pre-implementation data show baseline median for this metric was 87%. The targeted performance goal was an increase of 2.5% by performance year one and a 10% increase from baseline in performance year two.

11. Ensuring a bowel regimen is ordered when opioids are administered – Numerator: patients with recorded bowel regimen. Denominator: patients receiving opioids upon initial palliative care consult. Exclusion criteria: 17 years or younger, admission to palliative care <24h prior to discharge, or prior palliative care consult. Pre-implementation data show baseline median for this metric was 41%. The targeted performance goal was an increase of 10% by performance year one and a continued 2.5% increase from baseline per year thereafter.

Texas Children's Hospital Specific Metrics

12. Documenting code status conversations when code status is changed from "Full Code." Numerator: patients with Intubation Only, DNE, or NO CPR orders and documentation on the day the order was changed. Denominator: Patients with Intubation Only, DNR, or NO CPR orders. Exclusion criteria: none. Pre-Implementation data show baseline median for this metric was 60%. The targeted performance goal was an increase of 10% by performance year one with sustained improvement thereafter.

13. Post-mortem consents accompanying the deceased to the morgue. Numerator: Number of printed Epic reports upon declaration of death. Denominator: inpatient deaths. Exclusion criteria: none. Pre-implementation data: no baseline available, as this metric was not being kept. The targeted performance goal was to obtain a baseline for this metric.

14. Provision of support from interdisciplinary services at time of death. Numerator: number of deaths attended by chaplain, social work and certified child life specialist. Denominator: number of inpatient deaths. Exclusion criteria: none. Pre-implementation data show a baseline of 64%. The targeted performance goal was an increase of 10% by performance year one.

Within the institution, the organ procurement organization (OPO) was not always being alerted when a potential organ donor met the clinical trigger and thus opportunities for donation were missed. The pathology division was not always able to determine if an autopsy had been ordered and often had difficulty determining to whom to send the results. These data were also not being systematically collected to help inform metrics and quality improvement. Critical services such as chaplaincy, social work and child life specialists were only informed of patient deaths 64% of the time and thus could not provide standard support to dying patients. Because pediatric end of life care and conversations vary widely and are starkly different compared to adults, we developed a navigator to help tailor pediatric needs and ensure quality care.

Design and Implementation Model Practices and Governance

The champions responsible for the selection of the information and technology interventions highlighted in the use case are Amy Jeppesen (information technology), Jessica Casas (clinician), Laura Loftis (clinician), Leah Peters (quality champion), Joy Hesselgrave (nursing leadership) and Tammy Kang (C-Suite).

- **Members of the care delivery team**
  - Requesting tools to improve care/workflow
    - Jessica Casas, MD, MPH
    - Laura Loftis, MD
  - Participating in the review and selection process
    - Jessica Casas, MD, MPH
    - Laura Loftis, MD
    - Amy Jeppesen, BSN
    - Leah Peters, APN, BSN
    - Joy Hesselgrave, RN
  - Testing and field testing the new interventions and workflow
    - Jessica Casas, MD, MPH
    - Laura Loftis, MD
    - Amy Jeppesen, BSN
    - Leah Peters, APN, BSN
    - Joy Hesselgrave, RN
    - Taryn Schuelke, BA
    - Nick Ryan King Magdoza, BS
  - Serving as a champion as part of the education, training and implementation of the new workflow
    - Jessica Casas, MD, MPH
    - Laura Loftis, MD
    - Amy Jeppesen, BSN
    - Leah Peters, APN, BSN
    - Joy Hesselgrave, RN
    - Nikashia Franklin
    - Melody Hellsten

- **Participants on committees responsible for governance and change management of the underlying solutions and IT tools described in the use case**
    - Amy Jeppesen
    - Jessica Casas
    - Warren Boudreau
    - Tonita Powell-Fontenot
    - Devin Olivares-Reed
    - Heather McCarthy
    - Kenneth Kocab
    - Venkatesh Kancharla

Workflow Design and Solution Selection, Testing and Field Testing

The navigator streamlines workflow and provides a centralized location for documenting work surrounding end of life care. Activities outside of the EHR that can be prompted or documented within Epic are included (such as keepsakes, spiritual end of life rituals). Documentation is centralized so that all the work can be performed in one navigator. Documentation outside of Epic (for example autopsy consent) was brought into hyperspace. The field testing process included meeting frequently with stakeholders (for example, intensive care unit physicians and nurses where pediatric deaths most frequently occur) to ensure that the workflow was effective and efficient. We also performed in-person presentations in the play environment for physicians and nurses during division meetings and during rounds. Feedback was incorporated into the build and the feedback cycle was repeated prior to go-live.

Tools, Resources and Timeline

We trained providers by doing demonstrations at monthly staff meetings. We focused the training on nurses and physicians. Nurses received training as part of their quarterly training track. For all roles (including chaplaincy, social work, child life, the organ procurement organization representatives) we prepared extensive training resources, including step-by-step documentation, screenshots, and e-modules prior to go-live. We also presented these modules at faculty meetings in all pertinent divisions and were available for on-the-job training opportunities. The training took place three months prior to go-live and continued for six months after go-live. We continue to reach out to nursing and physician leadership throughout the hospital to ensure that the workflow meets their current needs and meet with their groups as needed to ensure optimization.

Clinical Transformation through Information and Technology

The End-of-Life Navigator (EOLN) has become a novel centralized tool that maximizes use of the electronic medical record to enhance communication between the medical team and patient/family, improve patient safety, clarify limitations, collect data to inform metrics and improve communication between the hospital and the organ procurement organization. All medical providers involved in the patients care document in the EOLN (nursing, physicians, social work, child life specialists, chaplains, organ procurement organization when applicable). Note templates within the EOLN are built through smart text to maximize data collection and billing.

See attached Process Map for Pediatric Palliative Care Patient Presenting at Near End-of-Life.

The nursing workflow for end of life care is now streamlined and exclusively uses the EOLN everywhere in the hospital (and at the community sites). It includes step by step guidance on who to call, what resources and support systems to offer the family, and what consents needs to be filled out, signed and printed. Prior to the EOLN, this information was found in different places and on paper. As such, previously, families received different care and support depending on where they were in the hospital or depending on the team's experience rather than on standard of care.

Artificial Intelligence

When the Pediatric Palliative Care Consult note (SmartText) is signed, it triggers the patient to be included in the denominator for the aforementioned Joint Commission and DSRIP metrics. Note templates within the EOLN are built through SmartData Elements to maximize data collection and billing. These data are electronically extracted into the Clarity database and are visualized in Qlikview dashboard.

Leveraged Algorithms

We have included the Modified Bereavement Risk Index (MBRI) in the EOLN. Each family can be stratified as high, medium or low risk in bereavement based on information related to four areas of coping (guilt, anger, family support and general coping needs). This helps guide the team in how to support the family during admission and after discharge and/or death.

Clinical Decision Support Best Practices

A code status order set was created. Any order (full code, intubation only, do not escalate, no CPR) prompts the order set to appear. The order set necessitates only one active order at a time. The order set prompts the clinician to indicate in a drop down calendar the date that the code status note was written. While the order can be signed without writing the note, the order cannot be signed without indicating the date which the note was written. This indirectly prompts the clinician to ensure that the note is written on the day they indicate in the medical record.

A corresponding note called Code Status Planning was developed along with a dot phrase that can be used in any progress note. An Epic report electronically pulls template and dot phrase use (see screenshots following this section).

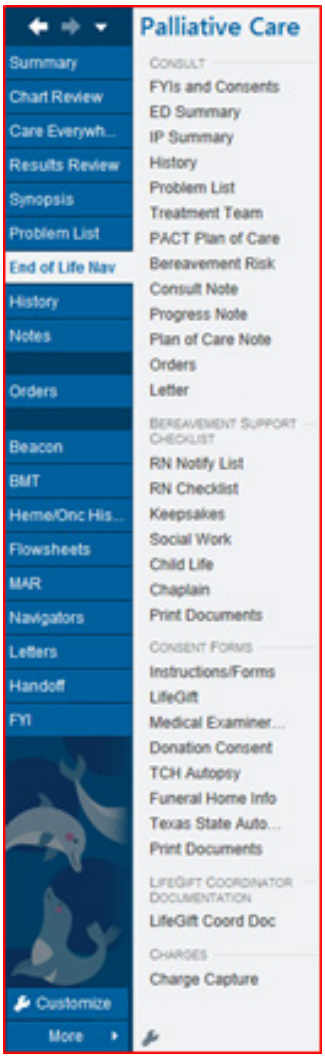
Changes in Care

The standard of care changed in late 2018, when the code status order set was adjusted to prompt the clinician to fill out the date which the code status note was written. After this implementation greater than 90% of code status changes had corresponding documentation.

Tools and Resources Facilitating Improved Patient Safety

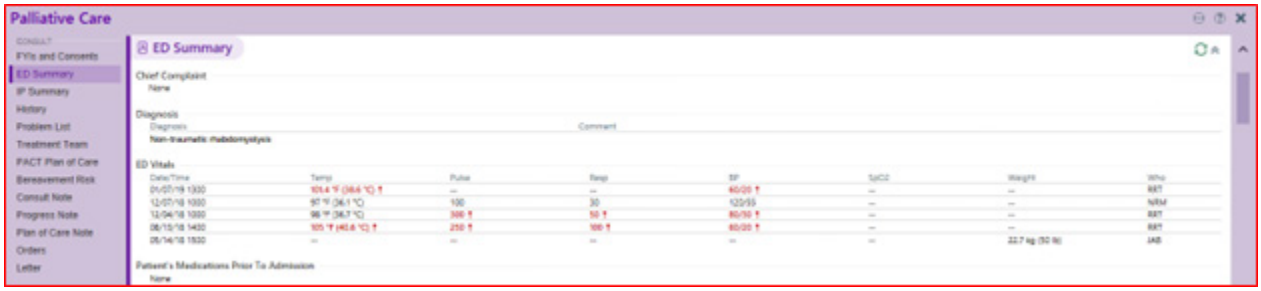
Using human factor engineering in the electronic medical record has enabled consistent documentation when code status changes. This ensures compliance with our state law and has resulted in goal concordant care.

The withdrawal of life sustaining therapies (WOLST) note template and dot phrase is a summary of the pre-WOLST huddle and provides medical recommendations for opioid and benzodiazepine management during the removal of life sustaining technology. At the end of life, the risk of not appropriately treating pain and dyspnea results in preventable suffering for patients and their families. The recommendations ensure appropriate weight-based therapy for many patients who are opioid and benzodiazepine habituated and supports the front line clinician in their medical decision making (screenshot below).

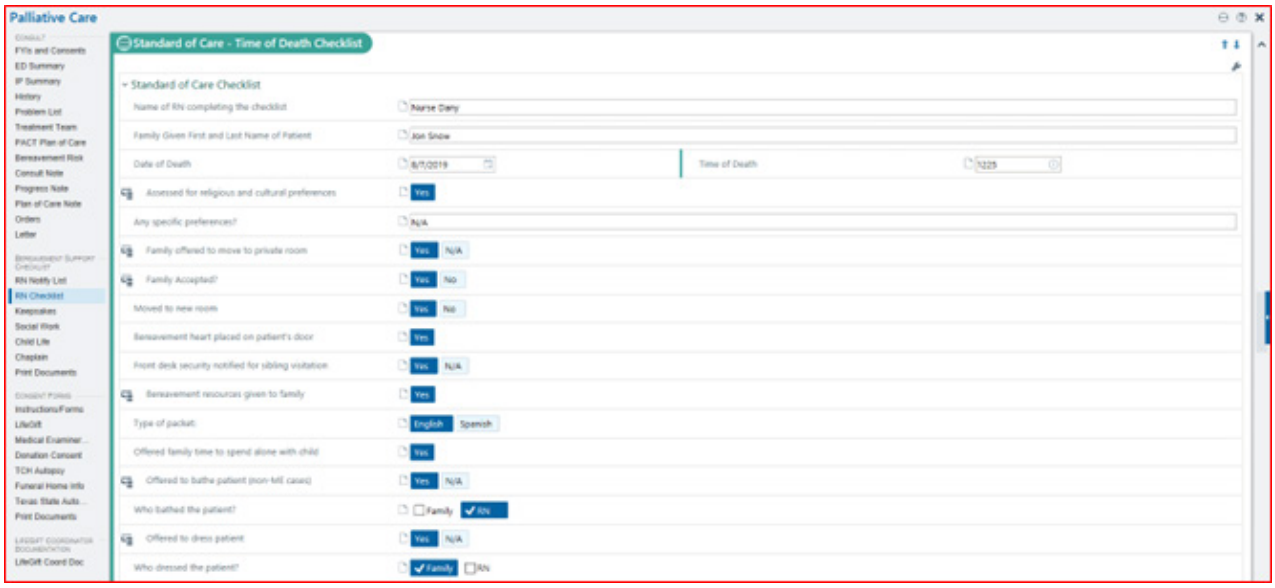


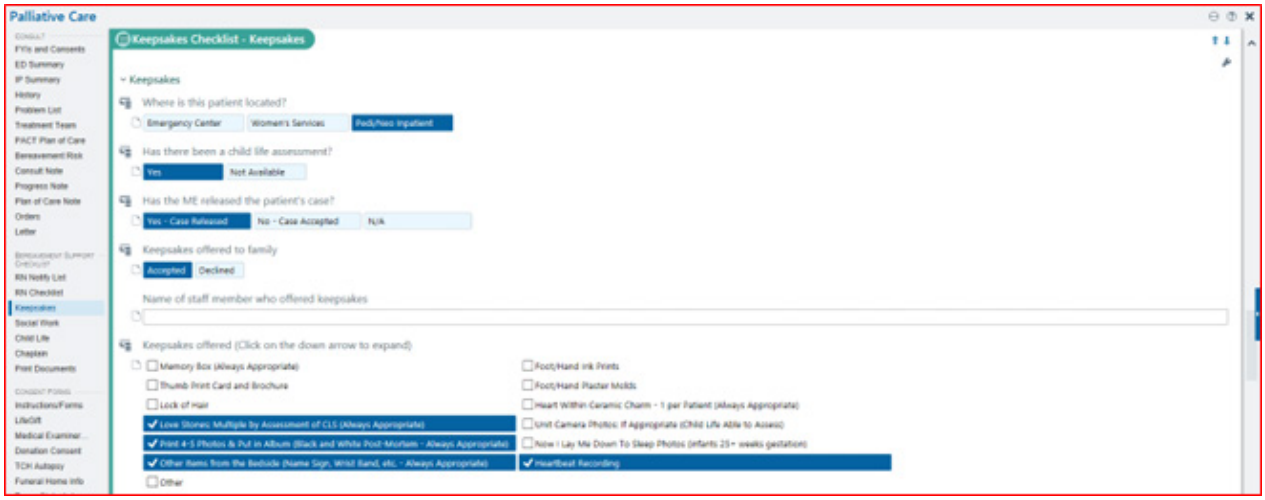
- **Consult:** Note templates for code status changes, plans of care
- **Bereavement Support Checklist:** interdisciplinary team involvement, RN to notify child life, social work, chaplaincy in every case
- **Consents Forms:** for autopsy, funeral home information, communication with the organ procurement organization
- **OPO Documentation:** space for communication with team

Consults and Bereavement Risk Scale

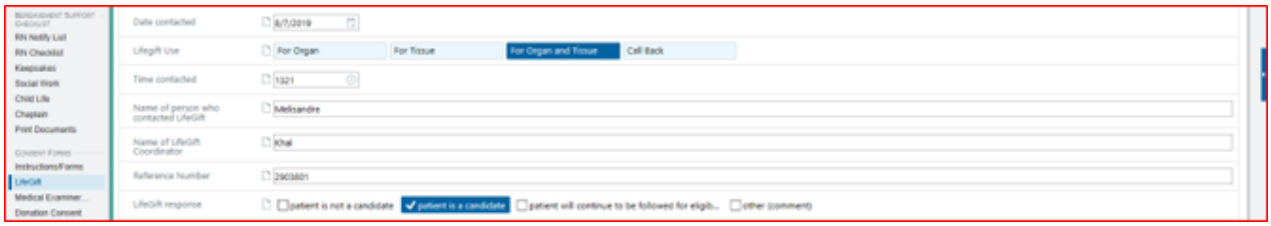


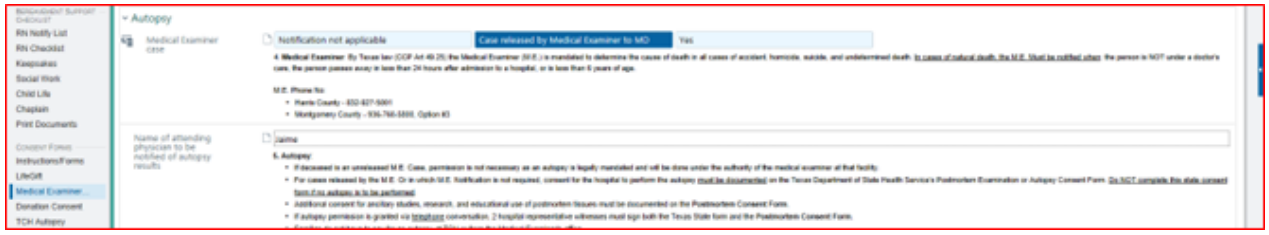
Bereavement Checklist

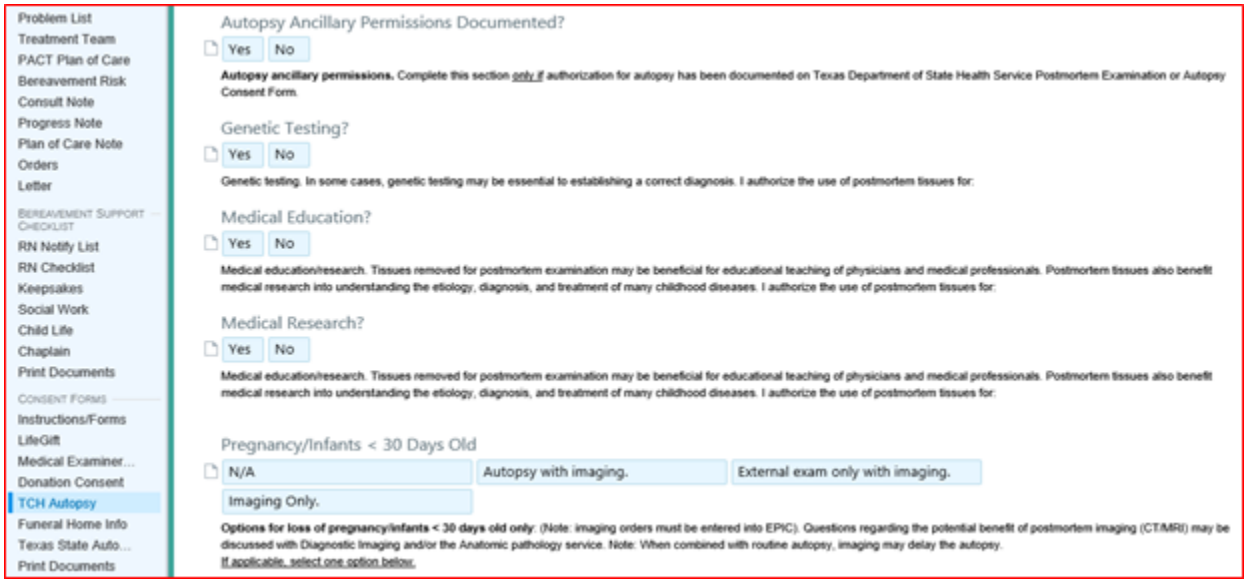




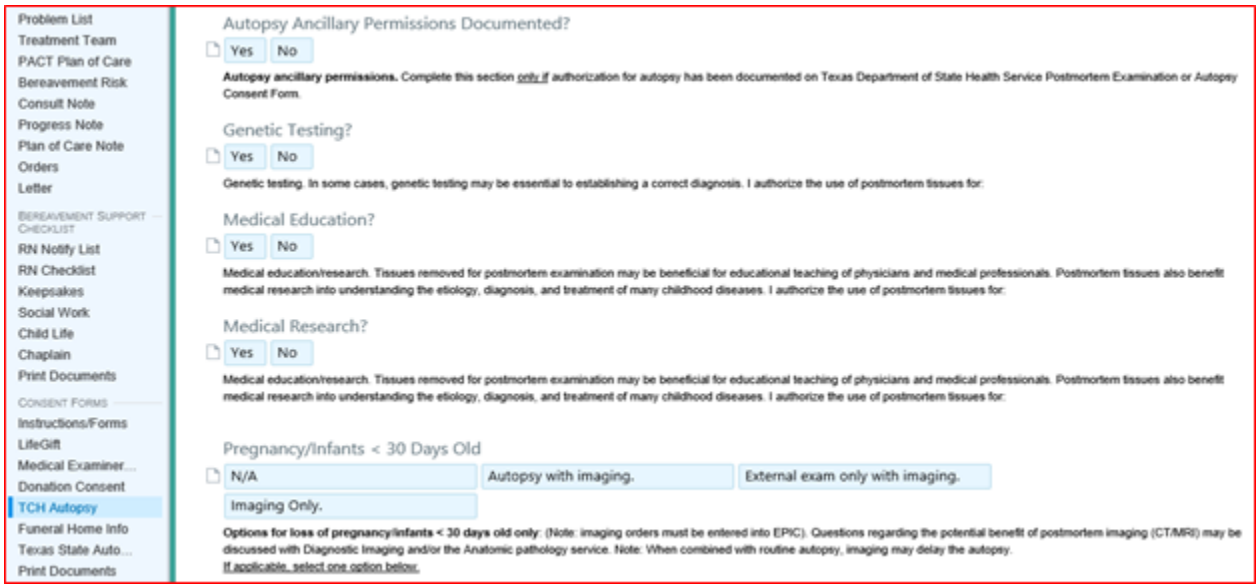
Consent Forms, Autopsy, Medical Examiner Information



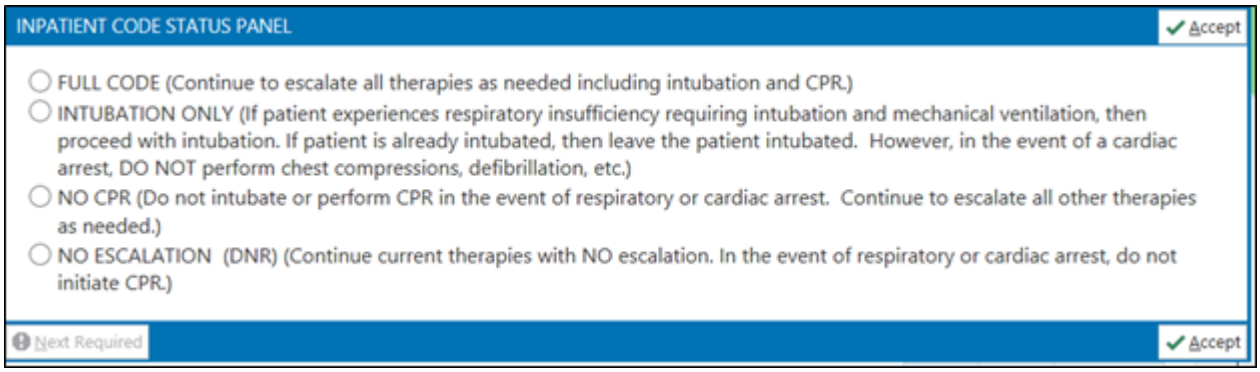




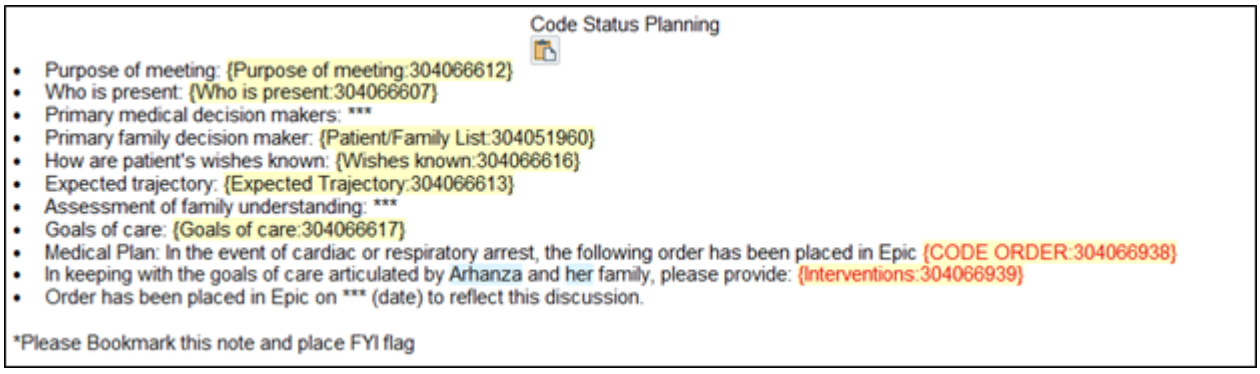
Organ Procurement Organization Documentation



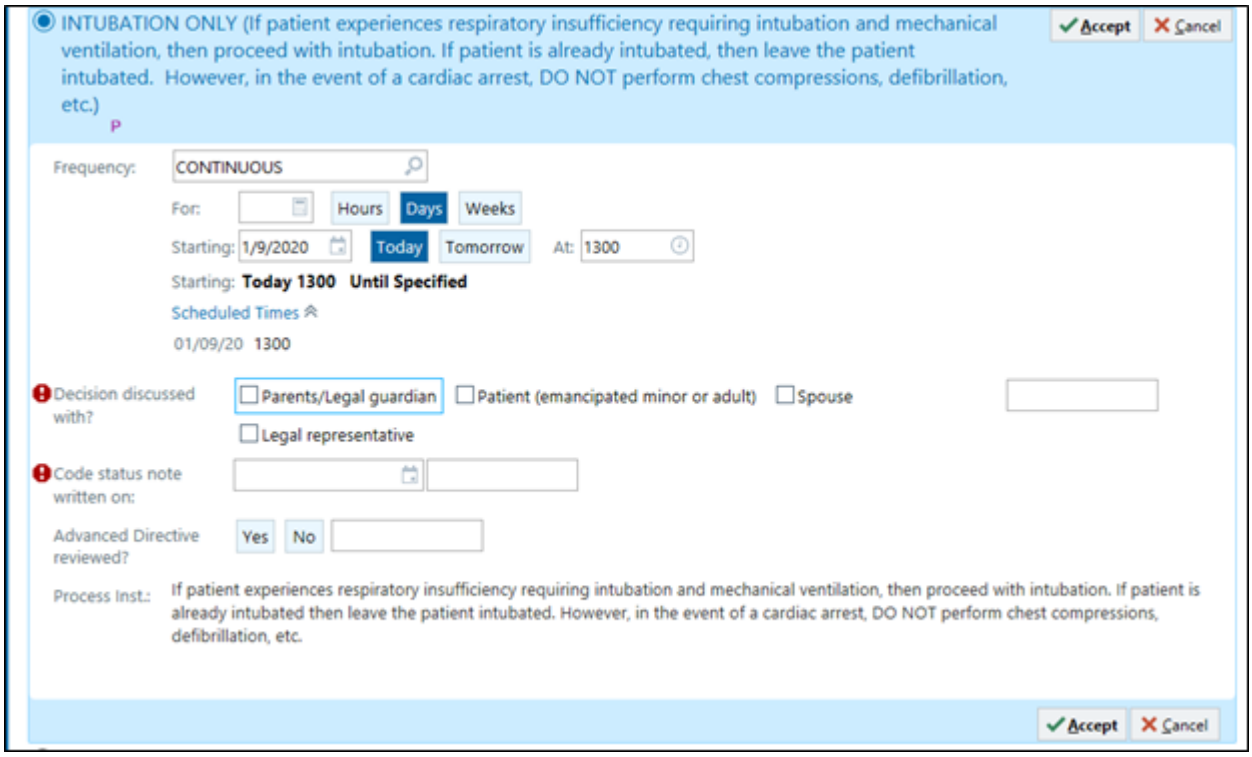
Code Status Documentation PDSA Cycle 1 – Inpatient Code Status Order Panel



PDSA Cycle 2 –Code Status Planning Note Template



PDSA Cycle 3 - Code Status Order Change and Required Documentation



WOLST Epic Dot Phrase

Withdrawal of Life-Sustaining Therapies Plan

The medical team met to discuss the care of @name@. Considering that the patient's disease process is terminal and/or irreversible, it is appropriate to pursue withdrawal of life-sustaining therapies (WOLST) and focus on comfort measures at the end-of-life.

The following members were present for interdisciplinary team meeting: **Drop down:** attending physician, fellow, resident, advance practice provider, nurse, respiratory therapist, SW, CCLS, Chaplain, interpreter, family, ***

Current Location: Drop down: NICU, PICU, CVICU

Planned location for WOLST: Drop down: NICU Butterfly room or bereavement transition room, move to private room, remain in current bedspace, ***

Respiratory support

Current support: **Drop down:** room air, NC, HFNC, CPAP, BiPAP, mechanical ventilation, HFOV, ECMO

Tracheostomy: **Drop down:** yes, no

Plan during withdrawal:

If trach question yes, autopopulate: The tracheostomy will be left in place, disconnected from respiratory support, and HME applied. The tracheostomy will not be capped.

If CPAP or BiPAP selected, autopopulate: **Drop down:** CPAP or BiPAP will be transitioned to nasal cannula or room air; based on patient's comfort, CPAP or BiPAP will remain in place for patient's comfort

If mechanical ventilation selected, autopopulate: **Drop down:** The ETT will be removed; the ETT will remain in place and the ventilation mode set to pressure support

If HFOV selected, autopopulate: **Drop down:** transition to conventional ventilator; extubate

If ECMO selected, autopopulate: The decision to decannulate vs clamp and turn off the ECMO machine is being discussed with the ECMO team

Oral and Airway Secretions

Current secretion management: **Drop down:** glycopyrrolate, scopolamine patch, atropine sublingual drops, ***

Plan for symptom monitoring and dose adjustments: **Drop down:**

- Patient not currently on a medication for secretions, and do not anticipate at this time that this will be an issue
- Patient not currently on a medication for secretions, but anticipate that this will be an issue. Will administer glycopyrrolate (40mcg/kg/dose) 30min prior to extubation
- Will continue current regimen, and maximize therapy. Will add another agent if needed for advancing symptoms

Dyspnea

Current dyspnea management: **Drop down:** morphine, hydromorphone, ***

Plan for symptom monitoring and dose adjustments: **Drop down:**

- Will continue current therapy as long as patient comfortable
- Patient not currently on an opioid, so will start morphine 0.05mg/kg/dose prn q15m if dyspnea apparent
- Patient currently on an opioid infusion, will increase current infusion by 50-100% based upon symptoms and increase PRN dose to match hourly rate if dyspnea present
- ***

Pain

Current medications: **drop down:** morphine, hydromorphone, fentanyl, methadone, ketamine, gabapentin, NSAIDs, acetaminophen, ***

Plan for symptom monitoring and dose adjustments: **drop down:**

- Patient not currently on an opioid, so will start morphine 0.1mg/kg/dose prn q15m if pain apparent
- Patient currently on an opioid infusion, will increase current infusion by 50-100% based upon symptoms and increase PRN dose to match hourly rate if in pain
- ***

Agitation / Anxiety

Current medication: **Drop down:** lorazepam, midazolam, ***

Plan for symptom monitoring and dose adjustments: **Drop down:**

- Will continue current therapy as long as patient comfortable
- Patient not currently on a benzodiazepine, so will start lorazepam 0.1mg/kg/dose q15min prn agitation or anxiety
- Patient currently on a benzodiazepine infusion, will continue as long as comfortable, increase infusion by 50-100% based upon symptoms and increase PRN dose to match hourly rate
- ***

Delirium

Current management: Drop down: haloperidol, risperidone, quetiapine, ***

Plan for symptom monitoring and dose adjustments: Drop down:

- Will continue current therapy as long as patient comfortable
- If delirium develops, will start haloperidol 1mg IV q4h prn for acute symptoms and titrate the dose up as needed.
- If delirium continues, will add an atypical antipsychotic
- ***

Nausea/Vomiting

Current management: Drop down: Zofran, Kytril, Benadryl, phenergan, haloperidol, Aprepitant, lorazepam

Plan for symptom monitoring and dose adjustments: Drop down:

- Will continue current therapy as long as patient comfortable
- If N/V worsens, will maximize current anti-emetic regimen and consider adding another class of agents
- ***

Other medications

Neuromuscular blockade

Current chemical paralysis: Drop down: yes, no

If yes, autopopulate: As soon as the decision to withdrawal life-sustaining therapies was made, the team discussed discontinuing neuromuscular blockade. The decision was made to discontinue the medication at ***, as this is the earliest time prior to withdrawal that the patient will likely tolerate its removal.

Pressors

Current medication(s): Drop down: epinephrine, norepinephrine, dopamine, vasopressin, calcium, milrinone, hydrocortisone, ***

Plan for withdrawal: Drop down:

- Will continue current therapy as long as patient comfortable
- Will wean *[medications selected above]* gradually over the next *** hours
- Will discontinue *[medications selected above]* at time of withdrawal of life-sustaining therapies
- ***

Lasix drip

Current continuous diuretic administration: Drop down: yes, no

If yes, autopopulate: Drop down:

- Will continue current therapy as long as patient comfortable
- Will discontinue at time of withdrawal of life-sustaining therapies
- ***

Oral & inhaled medications

Current oral medications, including: ***

Plan for dose adjustments: Drop down:

- Will discontinue all oral and inhaled medications at time of withdrawal of life-sustaining therapies
- Will continue to make *** available for symptom management
- ***

Nutrition & Hydration

Current nutrition regimen: Drop down: Formula, clears, full diet as tolerated, IV fluids, TPN/IL

Plan for nutrition and hydration: Drop down:

- Reduce TPN/IL or IVF rate by half
- Discontinue TPN/IL or IVF
- Allow PO for comfort as tolerated, monitor for signs of aspiration that cause discomfort
- Discontinue feeds
- ***

Access

Will remove these lines and tubes: Drop down: PIV, PICC, arterial line, umbilical lines, central line, ETT, chest tube, Foley, PD or HD cath, OG/NG/GT

All other lines and tubes will remain in place.

Memory making

Child Life Specialist has been contacted

Family has expressed interest in Drop down: making hand or foot molds, making hand or foot ink prints, collecting locks of hair, photography

Family needs

Social Work has been contacted.

The family Drop down: is waiting for *** to arrive, is waiting for *** circumstances, requests support for siblings aged ***, needs help identifying funeral home, ***

Spiritual needs

Chaplain has been contacted.

Family has expressed particular end of life rituals that are important to them that include: ***

Patient and/or family expressed religious preferences: Drop down: Christian, Catholic, Jehovah's Witness, Later Day Saints (Mormonism), Judaism, Islam, Hinduism, Buddhism, ***

If Christian, Catholic, Jehovah's Witness, or Later Day Saints selected, autopopulate: Family has expressed interest in Drop down: baptism, anointing of the sick (last rites), prayer

Family has expressed interest in working with Drop down: hospital chaplain, a Catholic priest, their own clergy, Imam.***

Cultural and personal needs

Family has expressed particular end of life rituals that are important to them that include: ***

Family would also like: Drop down: a bed in which they can lay with the patient, *** music playing, visitors to be shown into the room, visitors to be asked to wait outside, monitors left on, monitors turned off, ***

Consent to Autopsy: yes, no

Lifegift notified: yes, no

Improving Adherence to the Standard of Care (Guideline: One Page)

As a new sub-specialty in pediatrics, there is only one national benchmarking metric for inpatient pediatric palliative care (pain screening). We have adapted adult palliative metrics from The Joint Commission and the federal DSRIP to demonstrate gold standard care. Our site is maximizing use of the electronic health record to drive the development of national quality indicators for inpatient pediatric palliative care. Part of the implementation includes development of SmartText to standardize notes, workflow and documentation for pediatric palliative care thereby standardizing care delivered.

The metrics for Joint Commission (data steward) certification include the following and are chart-abstracted currently through we are in the process of making them eCOM.

1. **Screening for pain –** Numerator: patients with recorded pain screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: use of neuromuscular blocking agents. Pre-implementation data show baseline median for this metric was 86%. The current median is 100%, sustained over the last three years. This is the only metric for which there is a national benchmark (90%).

2. **Screening for dyspnea –** Numerator: patients with recorded pain screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: use of neuromuscular blocking agents. Pre-implementation data show baseline median for this metric was 56%. The current median is 100%, sustained over the last three years. There is no national benchmark for this metric in pediatrics.

3. **Performing a pain assessment when pain is reported –** Numerator: patients with five descriptors of pain assessment. Denominator: patients reporting presence of pain. Exclusion criteria: use of neuromuscular blocking agents. Pre-implementation data show baseline median for this metric was 38%. The current median is 100%, sustained over the last three years. There is no national benchmark for this metric in pediatrics.

4. **Documenting treatment preferences –** Numerator: patients with recorded treatment preferences. Denominator: patients receiving a palliative care consult. Exclusion criteria: none. Pre-implementation data show baseline median for this metric was 100%. The current median is 100%, sustained over the last three years. There is no national benchmark for this metric in pediatrics.

5. **Communicating the treatment preferences to the referring pediatrician** – Numerator: patients with letter sent to pediatrician reporting treatment preferences and palliative care involvement. Denominator: any palliative care patient who was discharged alive from the hospital. Exclusion criteria: inpatient death or signed off from palliative care service. Pre-implementation data show baseline median for this metric was 9%. The current median is 89%, sustained over the last two years. There is no national benchmark for this metric in pediatrics.

DSRIP metrics include the following and are collected via eCOM starting in performance year one or performance year two. Texas Health and Human Services Commission (HHSC). Qlikview application validation is ongoing:

6. **Pain assessment at initial consult when pain is reported as >4/10 –** Numerator: new patients with five descriptors of pain documented. Denominator: patients reporting >4/10 pain on initial consult. Exclusion criteria: 1) Use of neuromuscular blocking agents. 2) Admission to palliative care < 24h prior to discharge. 3) no prior palliative care consult. Pre-implementation data show baseline median for this metric was 42%. The targeted performance goal was an increase of 2.5% by performance year one and 10% increase from baseline in performance year two. The current median is 85%, sustained over the last two years. There is no national benchmark for this metric in pediatrics.

7. **Dyspnea screen at initial consult –** Numerator: new patients with recorded dyspnea screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: 1) Use of neuromuscular blocking agents. 2) Admission to palliative care < 24h prior to discharge. 3) no prior palliative care consult. Pre-implementation data show baseline median for this metric was 54%. The targeted performance goal was an increase of 2.5% by

performance year one and 10% increase from baseline in performance year two. The current median is 94%, sustained over the last two years. There is no national benchmark for this metric in pediatrics.

8. Dyspnea treatment when dyspnea is identified at initial consult – Numerator: patients with recorded dyspnea treatment. Denominator: patients reporting dyspnea on initial palliative care consult. Exclusion criteria: 1) Use of neuromuscular blocking agents. 2) Admission to palliative care <24h prior to discharge. 3) no prior palliative care consult. Pre-implementation data show baseline median for this metric was 31%. The targeted performance goal was an increase of 2.5% by performance year one and 10% increase from baseline in performance year two. The current median is 54% sustained over the last two years. There is no national benchmark for this metric in pediatrics.

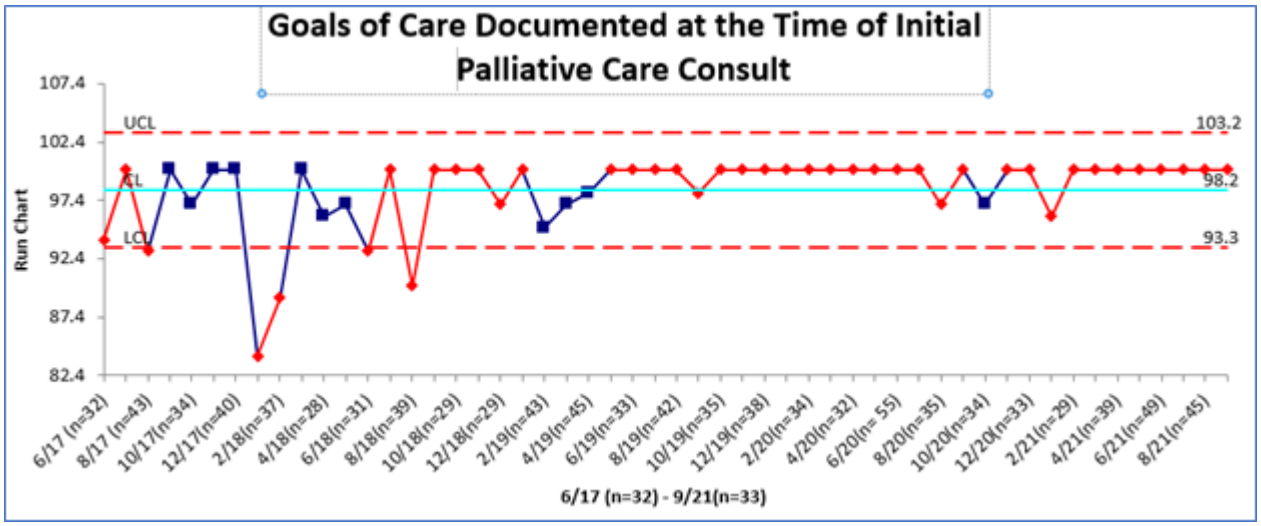
9. Documentation of spiritual beliefs and values – Numerator: patients with recorded spiritual screen. Denominator: patients receiving a palliative care consult. Exclusion criteria: 1) 17 years of age or younger. 2) Admission to palliative care <24h prior to discharge. 3) no prior palliative care consult. Pre-implementation data show baseline median for this metric was 71%. The targeted performance goal was an increase of 2.5% by performance year one and 10% increase from baseline in performance year two. The current median is 73% sustained over the last two years. There is no national benchmark for this metric in pediatrics.

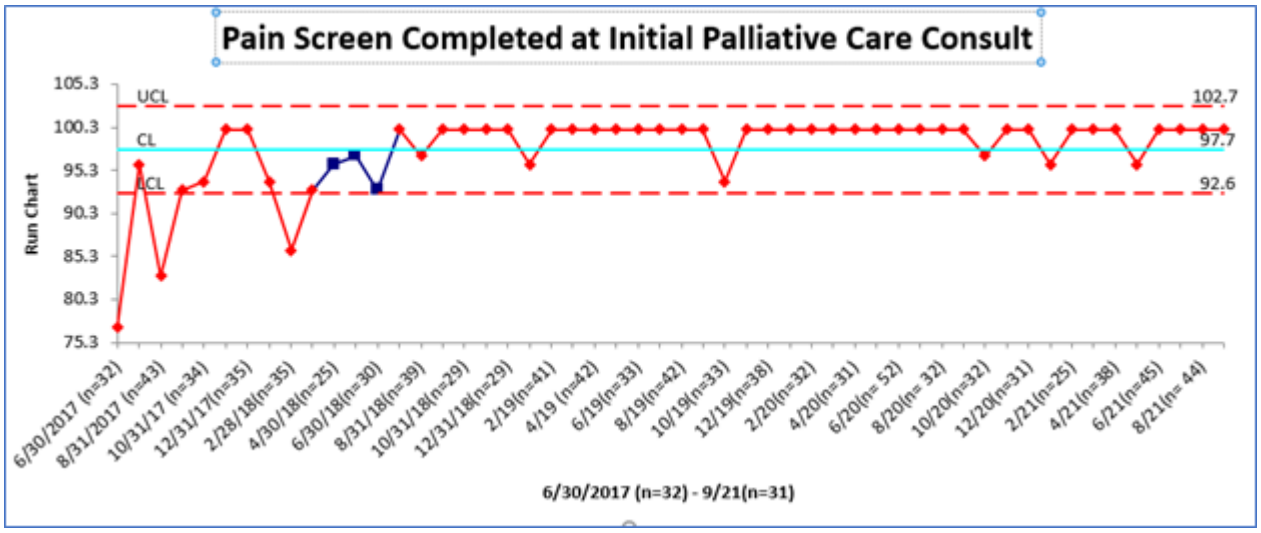
10. Identification of treatment preferences – Numerator: patients with recorded treatment preferences. Denominator: patients receiving a palliative care consult. Exclusion criteria: 1) Admission to palliative care <24h prior to discharge. 3) No prior palliative care consult. Pre-implementation data show baseline median for this metric was 87 The targeted performance goal was an increase of 2.5% by performance year one and 10% increase from baseline in performance year two. The current median is 96% over the last two years. There is no national benchmark for this metric in pediatrics.

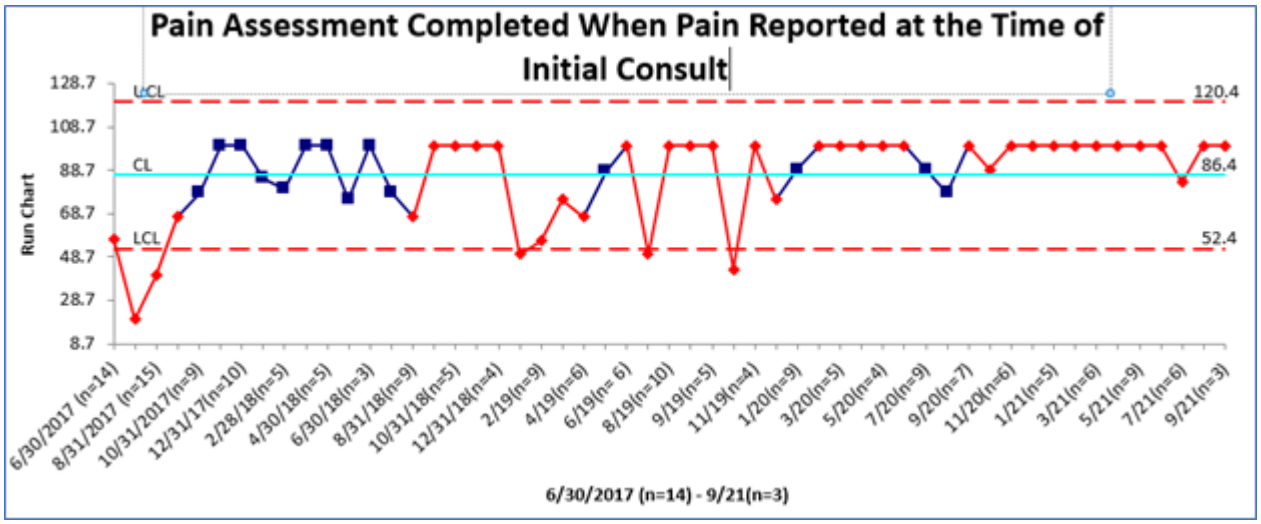
11. Ensuring a bowel regimen is ordered when opioids are administered – Numerator: patients with recorded bowel regimen. Denominator: patients receiving opioids upon initial palliative care consult. Exclusion criteria: 1) 17 years or younger. 2) Admission to palliative care <24h prior to discharge. 3) No prior palliative care consult. Pre-implementation data show baseline median for this metric was 41%. The targeted performance goal was an increase of 2.5% by performance year one and 10% increase from baseline in performance year two. Current median is 58% over the last two years. There is no national benchmark for this metric in pediatrics.

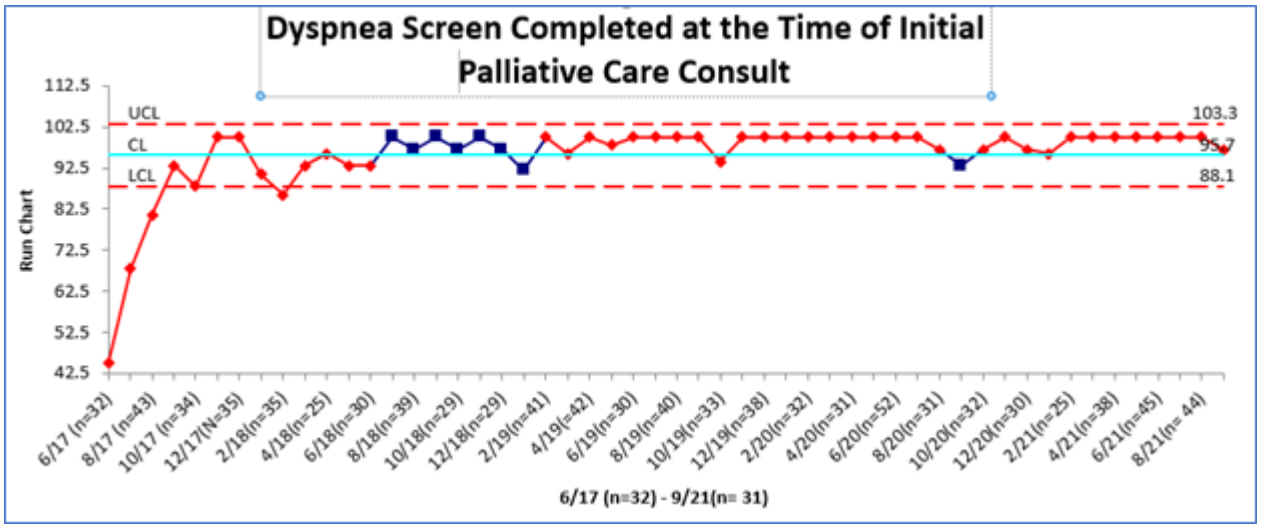
Texas Children's Hospital Specific Metrics: There was a new order set created for "Code Status." There was also a new workflow for nurses in end of care that standardized the care and support offered to families of dying children. These changes drove a spike in performance measures as below:

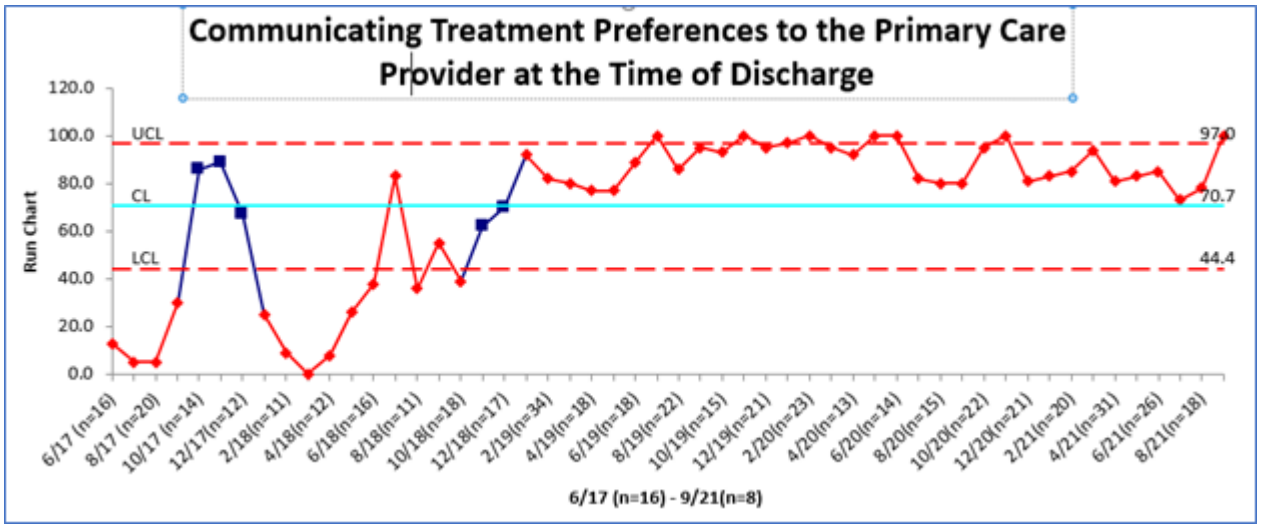
12. Documenting code status conversations when code status is changed from "Full Code." Numerator: patients with Intubation Only, DNE, or NO CPR orders and documentation on the day the order was changed. Denominator: Patients with Intubation Only, DNR, or NO CPR orders. Exclusion criteria: none. Pre-Implementation data show baseline median for this metric was 60%. The targeted performance goal was an increase of 10% by performance year one with sustained improvement thereafter. The median for this metric was 90% sustained over 12 months post implementation. There is no national benchmark for this metric.
13. Post-mortem consents accompanying the deceased to the morgue. Numerator: Number of printed Epic reports upon declaration of death. Denominator: inpatient deaths. Exclusion criteria: none. Pre-implementation data: no baseline available, as this metric was not being kept. The targeted performance goal was to obtain a baseline for this metric. The baseline for this metric is 100% as all inpatient deaths go through the EOLN.
14. Provision of support from interdisciplinary services at time of inpatient death. Numerator: number of deaths attended by chaplain, social work and certified child life specialist. Denominator: number of inpatient deaths. Exclusion criteria: none. Pre-implementation data show a baseline of 64%. The targeted performance goal was an increase of 10% by performance year one. The median for this metric was 80% 12 months after implementation of the EOLN.

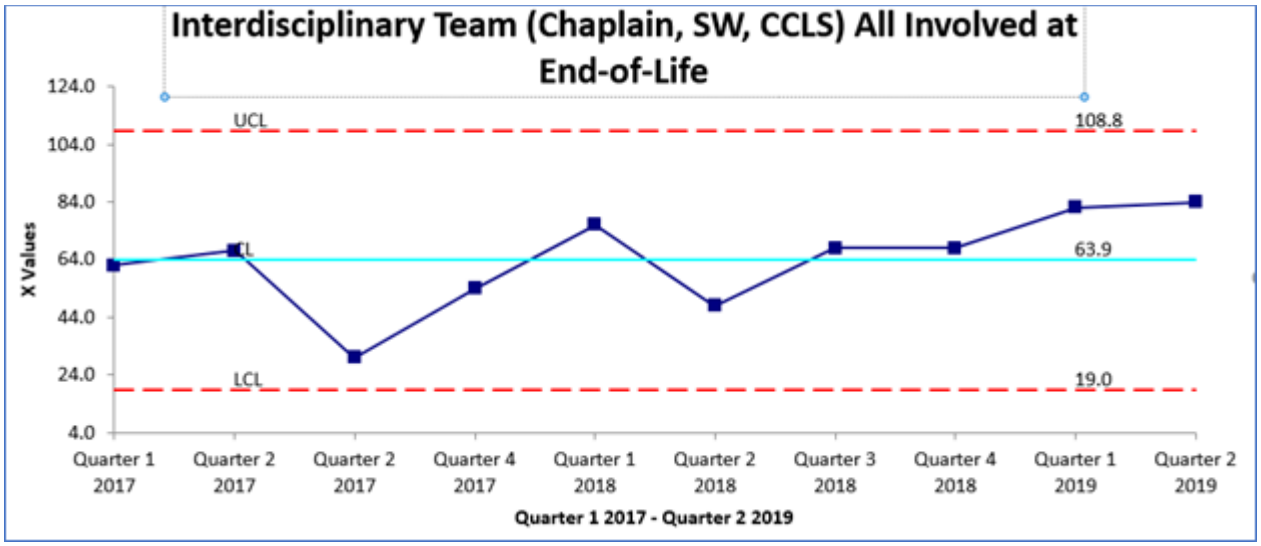


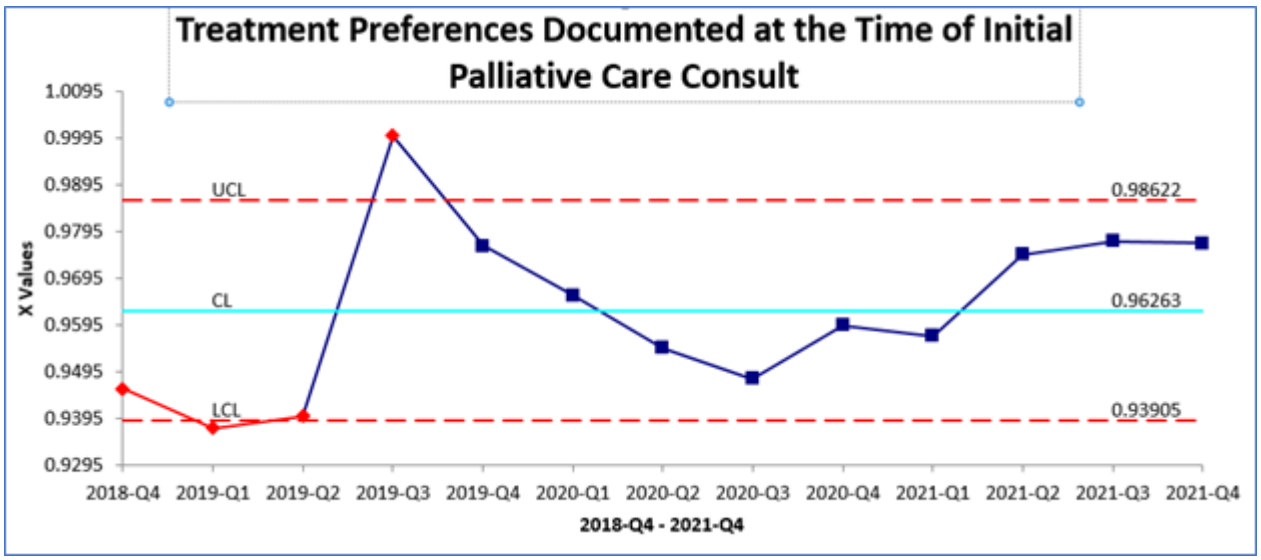

Pain Screen Completed at Initial Palliative Care Consult
Run Chart
UCL
CL
LCL
105.3
100.3
95.3
90.3
85.3
80.3
75.3
102.7
97.7
92.6
6/30/2017 (n=32)
8/31/2017 (n=43)
10/31/17 (n=34)
12/31/17(n=35)
2/28/18(n=35)
4/30/18(n=25)
6/30/18(n=30)
8/31/18(n=39)
10/31/18(n=29)
12/31/18(n=29)
2/19(n=41)
4/19 (n=42)
6/19(n=33)
8/19(n=42)
10/19(n=33)
12/19(n=38)
2/20(n=32)
4/20(n=31)
6/20(n= 52)
8/20(n= 32)
10/20(n=32)
12/20(n=31)
2/21(n=25)
4/21(n=38)
6/21(n=45)
8/21(n= 44)
6/30/2017 (n=32) - 9/21(n=31)

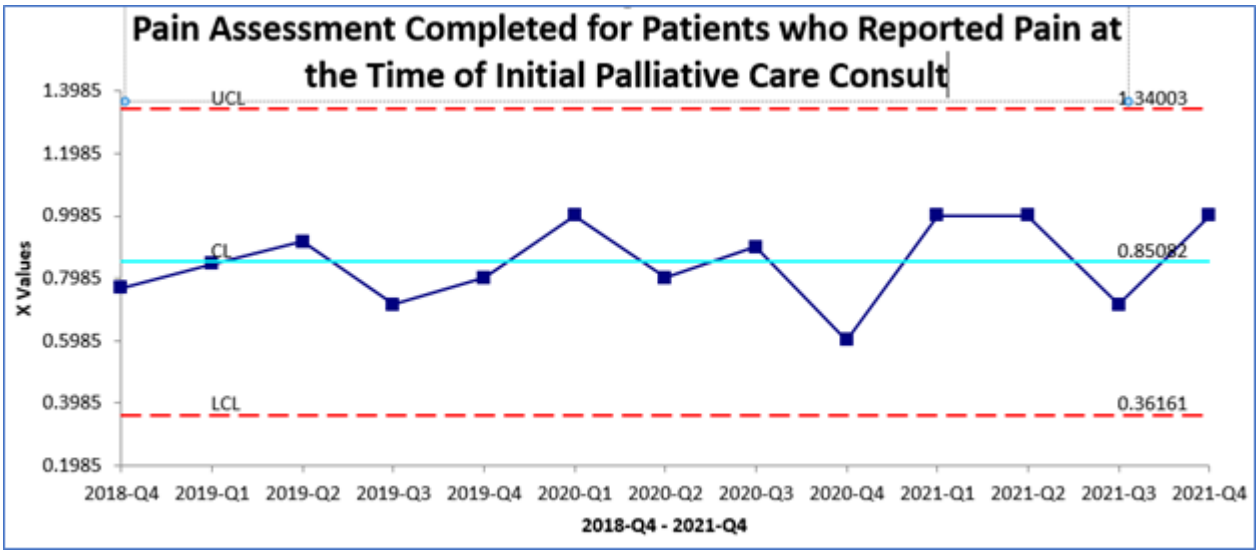

Pain Assessment Completed When Pain Reported at the Time of Initial Consult
Run Chart
UCL
CL
LCL
128.7
108.7
88.7
68.7
48.7
28.7
8.7
120.4
86.4
52.4
6/30/2017 (n=14)
8/31/2017 (n=15)
10/31/2017(n=9)
12/31/17(n=10)
2/28/18(n=5)
4/30/18(n=5)
6/30/18(n=3)
8/31/18(n=9)
10/31/18(n=5)
12/31/18(n=4)
2/19(n=9)
4/19(n=6)
6/19(n= 6)
8/19(n=10)
9/19(n=5)
11/19(n=4)
1/20(n=9)
3/20(n=5)
5/20(n=4)
7/20(n=9)
9/20(n=7)
11/20(n=6)
1/21(n=5)
3/21(n=6)
5/21(n=9)
7/21(n=6)
9/21(n=3)
6/30/2017 (n=14) - 9/21(n=3)

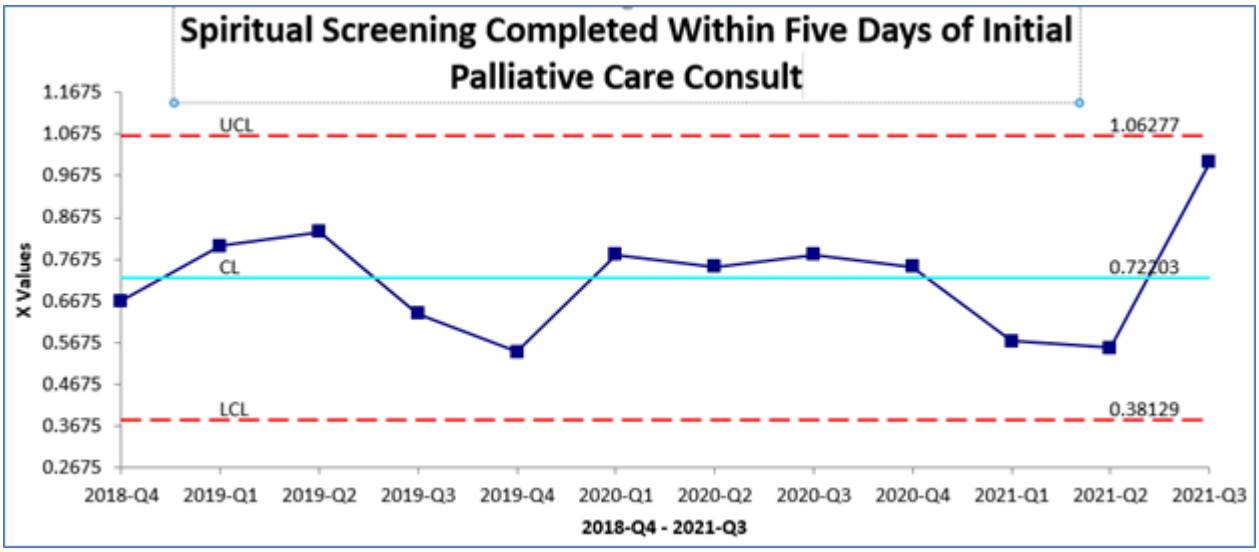

Dyspnea Screen Completed at the Time of Initial Palliative Care Consult
Run Chart
UCL
CL
LCL
112.5
102.5
92.5
82.5
72.5
62.5
52.5
42.5
103.3
95.7
88.1
6/17 (n=32)
8/17 (n=43)
10/17 (n=34)
12/17(N=35)
2/18(n=35)
4/18(n=25)
6/18(n=30)
8/18(n=39)
10/18(n=29)
12/18(n=29)
2/19(n=41)
4/19(=42)
6/19(n=30)
8/19(n=40)
10/19(n=33)
12/19(n=38)
2/20(n=32)
4/20(n=31)
6/20(n=52)
8/20(n=31)
10/20(n=32)
12/20(n=30)
2/21(n=25)
4/21(n=38)
6/21(n=45)
8/21(n= 44)
6/17 (n=32) - 9/21(n= 31)

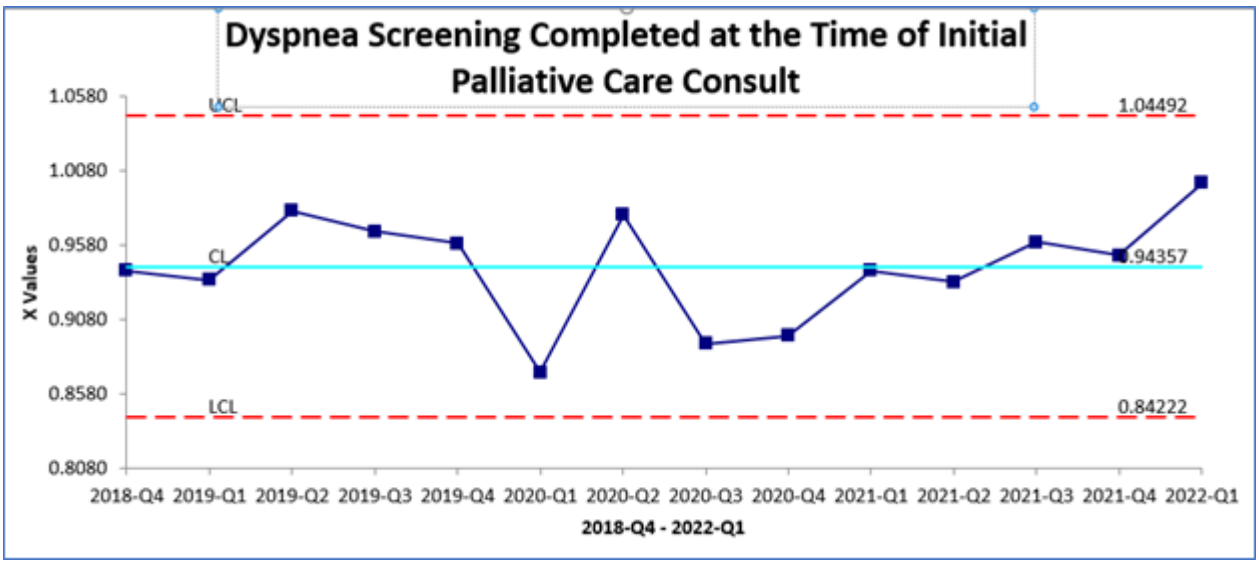

Communicating Treatment Preferences to the Primary Care Provider at the Time of Discharge
Run Chart
UCL
CL
LCL
97.0
70.7
44.4
6/17 (n=16) - 9/21(n=8)

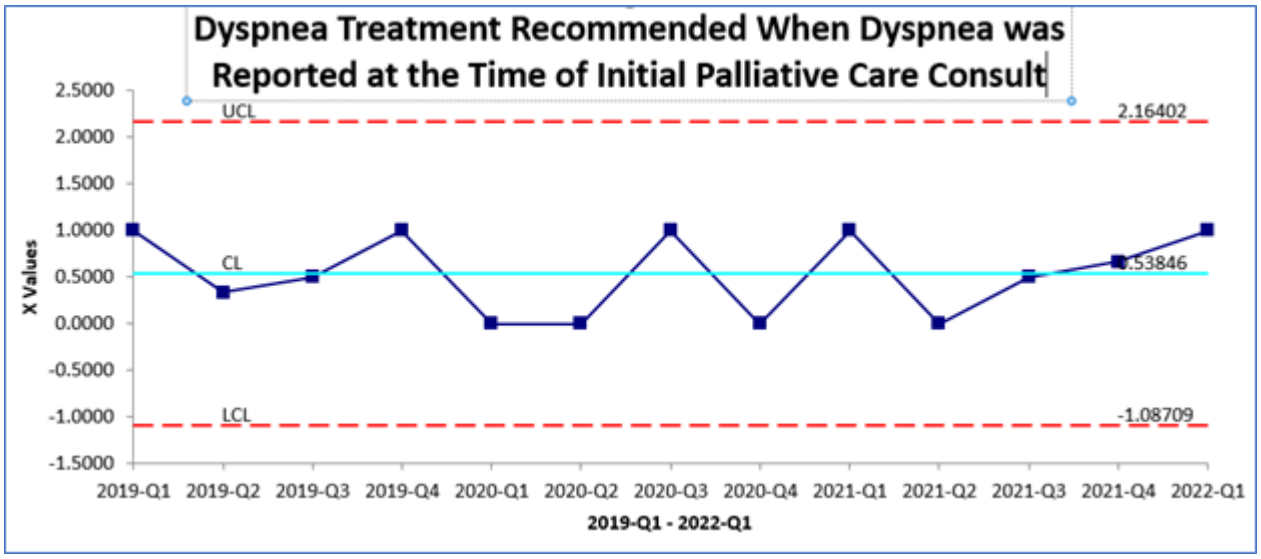

Interdisciplinary Team (Chaplain, SW, CCLS) All Involved at End-of-Life
X Values
UCL
CL
LCL
108.8
63.9
19.0
Quarter 1 2017 - Quarter 2 2019

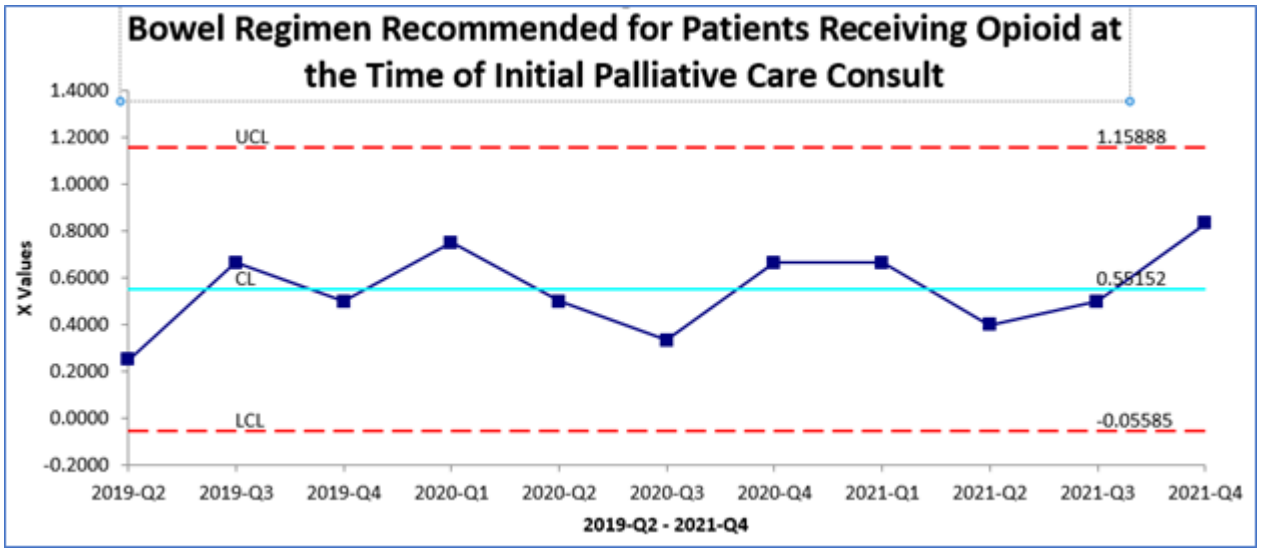

Treatment Preferences Documented at the Time of Initial Palliative Care Consult
X Values
UCL
CL
LCL
0.98622
0.96263
0.93905
2018-Q4 - 2021-Q4

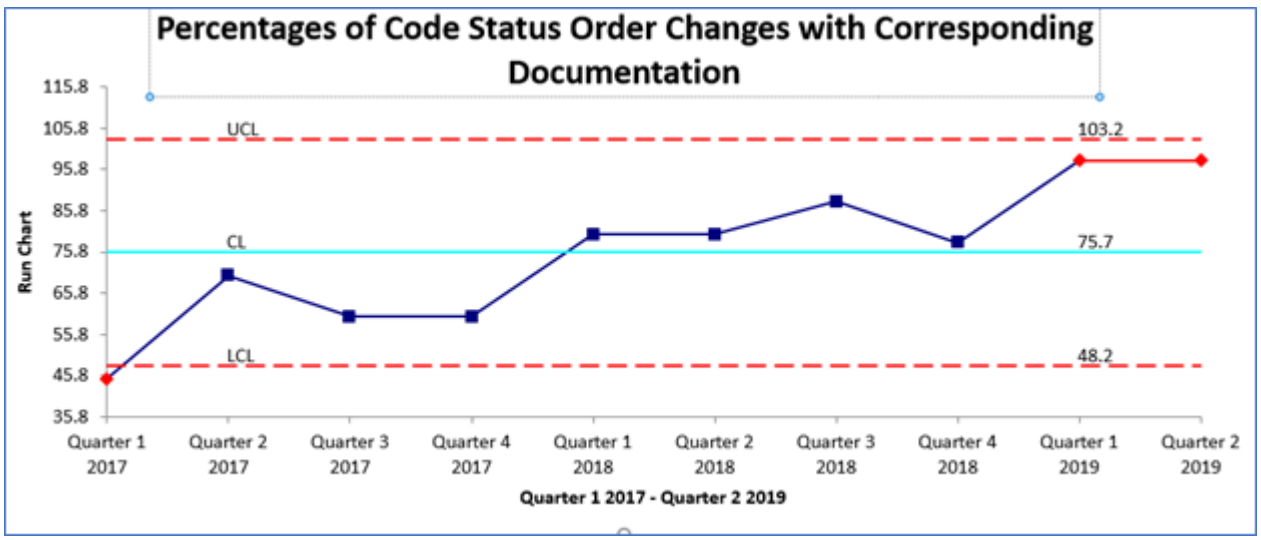

Pain Assessment Completed for Patients who Reported Pain at the Time of Initial Palliative Care Consult
UCL
1.34003
CL
0.85082
LCL
0.36161
X Values
1.3985
1.1985
0.9985
0.7985
0.5985
0.3985
0.1985
2018-Q4 2019-Q1 2019-Q2 2019-Q3 2019-Q4 2020-Q1 2020-Q2 2020-Q3 2020-Q4 2021-Q1 2021-Q2 2021-Q3 2021-Q4
2018-Q4 - 2021-Q4


Spiritual Screening Completed Within Five Days of Initial Palliative Care Consult
UCL
1.06277
CL
0.72203
LCL
0.38129
X Values
1.1675
1.0675
0.9675
0.8675
0.7675
0.6675
0.5675
0.4675
0.3675
0.2675
2018-Q4 2019-Q1 2019-Q2 2019-Q3 2019-Q4 2020-Q1 2020-Q2 2020-Q3 2020-Q4 2021-Q1 2021-Q2 2021-Q3
2018-Q4 - 2021-Q3


Dyspnea Screening Completed at the Time of Initial Palliative Care Consult
UCL
1.04492
CL
0.94357
LCL
0.84222
X Values
1.0580
1.0080
0.9580
0.9080
0.8580
0.8080
2018-Q4 2019-Q1 2019-Q2 2019-Q3 2019-Q4 2020-Q1 2020-Q2 2020-Q3 2020-Q4 2021-Q1 2021-Q2 2021-Q3 2021-Q4 2022-Q1
2018-Q4 - 2022-Q1


Dyspnea Treatment Recommended When Dyspnea was Reported at the Time of Initial Palliative Care Consult
UCL
2.16402
CL
0.53846
LCL
-1.08709
X Values
2.5000
2.0000
1.5000
1.0000
0.5000
0.0000
-0.5000
-1.0000
-1.5000
2019-Q1 2019-Q2 2019-Q3 2019-Q4 2020-Q1 2020-Q2 2020-Q3 2020-Q4 2021-Q1 2021-Q2 2021-Q3 2021-Q4 2022-Q1
2019-Q1 - 2022-Q1


Bowel Regimen Recommended for Patients Receiving Opioid at the Time of Initial Palliative Care Consult
UCL
1.15888
CL
0.58152
LCL
-0.05585
X Values
1.4000
1.2000
1.0000
0.8000
0.6000
0.4000
0.2000
0.0000
-0.2000
2019-Q2 2019-Q3 2019-Q4 2020-Q1 2020-Q2 2020-Q3 2020-Q4 2021-Q1 2021-Q2 2021-Q3 2021-Q4
2019-Q2 - 2021-Q4


Percentages of Code Status Order Changes with Corresponding Documentation
UCL
103.2
CL
75.7
LCL
48.2
Run Chart
115.8
105.8
95.8
85.8
75.8
65.8
55.8
45.8
35.8
Quarter 1 2017 Quarter 2 2017 Quarter 3 2017 Quarter 4 2017 Quarter 1 2018 Quarter 2 2018 Quarter 3 2018 Quarter 4 2018 Quarter 1 2019 Quarter 2 2019
Quarter 1 2017 - Quarter 2 2019

Improving Patient Outcomes and follow-up notes and dashboard

In pediatrics, the trajectories of life-limiting illnesses often take on a prolonged sinusoidal curve with a general decline over time. Goals and priorities for care may therefore change often and thus should be clearly updated accordingly in the EHR as clinically indicated, in an ongoing process and adapted to the individual family. In adult care, advance care planning navigators have been created; however, none have been described in pediatrics. Given the variable disease trajectories and prognoses that accompany pediatric care, a pediatric specific navigator was needed to address pediatric needs. This necessity drove the creation of a new navigator within the EHR at our institution. This project brought together key stakeholders in EOL care, addressed their major concerns, and created a solution using quality improvement (QI) science.

Prior to the implementation of the EOLN in Epic, there was not a centralized location to find or document critical end-of-life information. The EOLN has become a novel centralized tool that maximizes use of the electronic medical record to enhance communication between the medical team and patient/family, improve patient safety, clarify limitations, collect data to inform metrics and improve communication between the hospital and the organ procurement organization.

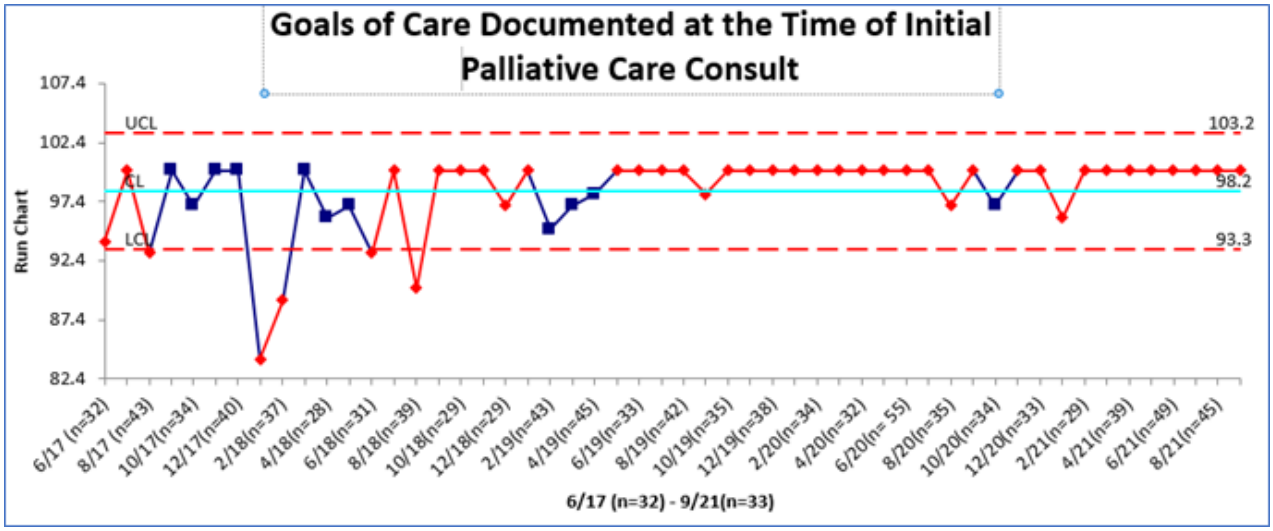
Since its implementation, greater than 90% of changes in code status have been accompanied by a note documenting the conversation resulting in the code status change. This contrasts with 60% in the year prior and has prevented families from having to repeat their wishes for limitations of resuscitation for their dying child. It also helps with the provision of goal concordant care at end of life.

The literature shows that inadequate pain control at end of life results in poor outcomes, increased suffering at end of life and complicated grief for surviving family. Thus, our metrics have focused on treatment of pain, dyspnea and uncomfortable symptoms such as opioid induced constipation. Pain screening and assessment in our patients improved by 14% and 60% respectively. Dyspnea screening and treatment improved by 40% and 20% respectively.

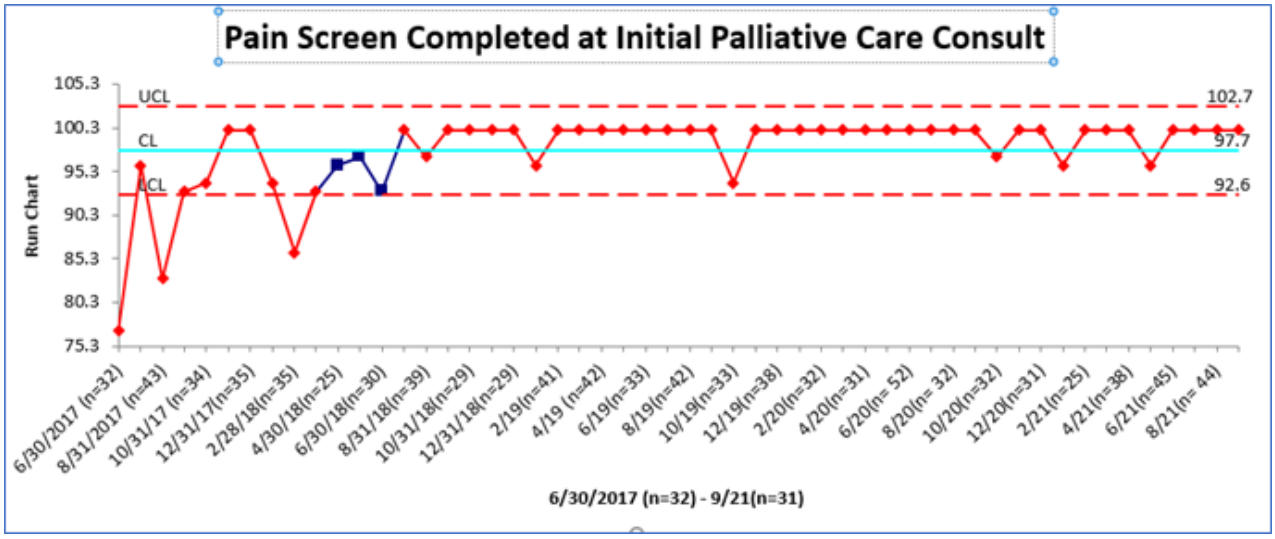
Ensuring that all patients receiving an opioid receive a bowel regimen improved from 41% to 58%. These tremendous, sustained improvements have led to more equitable patient care, enhanced patient experience and improved quality of life. In addition, we consistently record treatment preferences for all palliative care patients to ensure the delivery of goal concordant care. Recognizing that pediatric patients may have changing goals throughout their disease trajectories, we communicate treatment preferences to the primary pediatrician or primary sub-specialist 89% of the time (improved from 9%) to ensure wrap-around, patient centered care.

Data regarding potential organ donors is being reported to the OPO more consistently, quality metrics are being electronically collected surrounding pain and symptom management, treatment preferences and spiritual beliefs (Qlikview app validation is currently ongoing). In addition, deaths are attended by an interdisciplinary team greater than 80% of the time, thus providing maximum support at what is the most vulnerable time in a family's life. Prior to implementation of the navigator, some units did not have access to the bereavement checklist. Now it is used in our 900-bed system (including affiliate community children's hospitals) and thus increases staff resources and standardizes care around the EOL. Post implementation interviews with bedside nursing staff revealed that the navigator was easy to use, saved them time, increased the support that they were able to offer families and may explain the increase in psychosocial support consistently offered to families.

The navigator has become a novel centralized tool that maximizes use of the EHR to clarify limitations of interventions, collect data to inform metrics, support bedside nursing staff with EOL care, standardize the psychosocial support offered to families at EOL and computerize post-mortem paperwork. This implementation has led to accreditation by The Joint Commission and partnership with the Delivery System Reform Incentive Payment Program. Tailored to specific institutions, the EOLN has the ability to streamline work flow, efficiency and communication surrounding end of life care in children.



1. Dot phrase developed 6/17
2. Screens added to consult note template 8/28/17
3. Note template updated 10/31/2017
4. Reviewed data with team and with individuals. Reminder at weekly meetings 12/1/2017
5. Reminder at Faculty meeting 8/2018



1. Dot phrase developed 6/2017
2. Screens added to consult note template 8/28/2017
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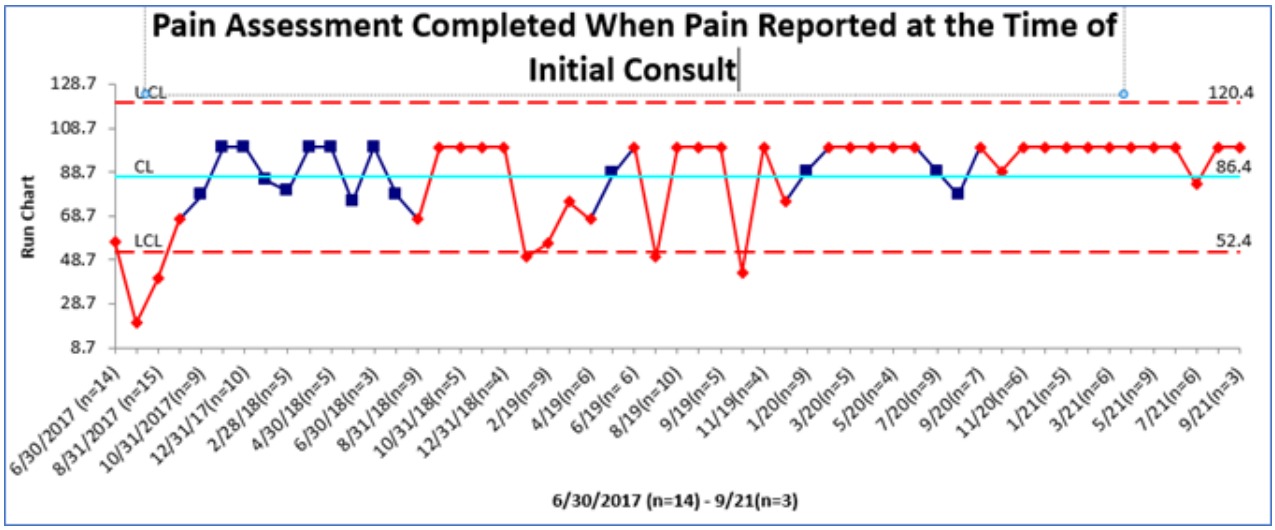
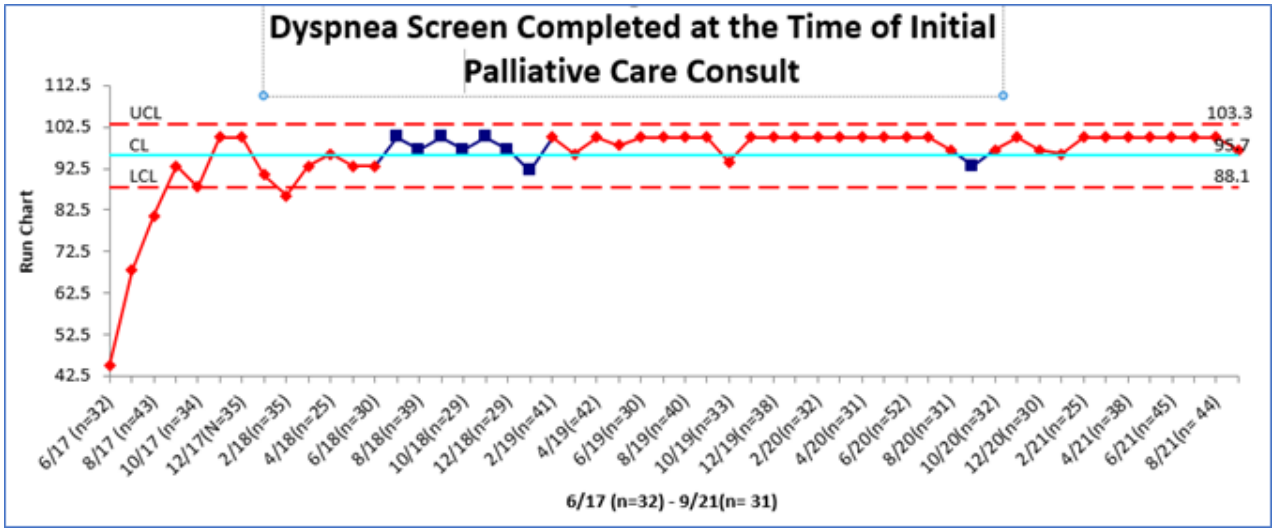
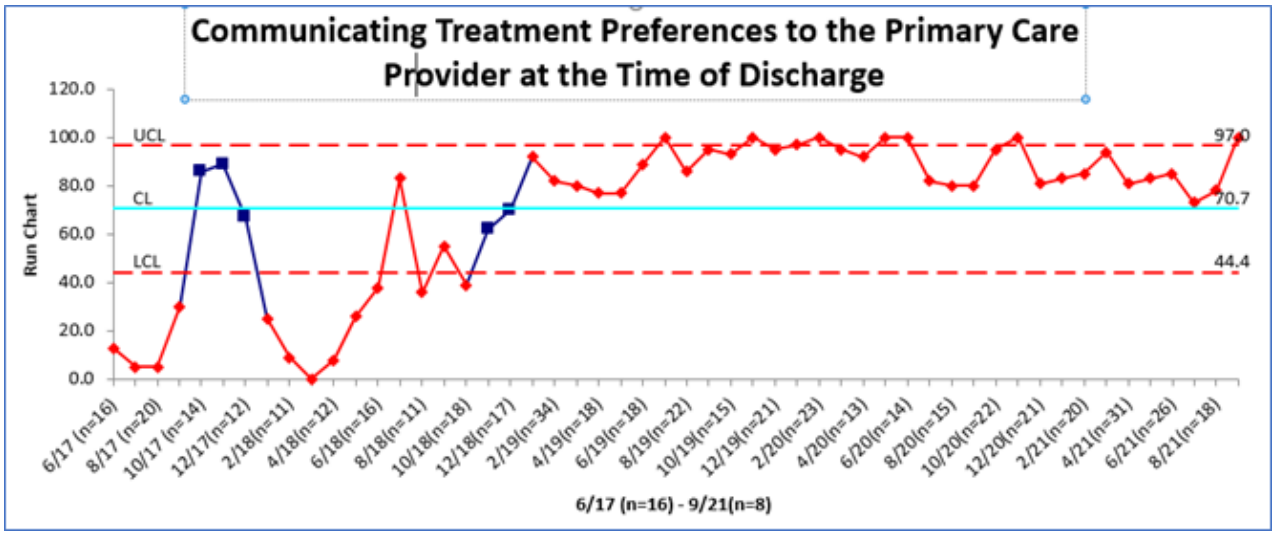
4. Reviewed data with team and with individuals. Reminder at weekly meetings 12/1/2017
5. Reminder at Faculty meeting 8/2018
6. Email reminder 10/2019



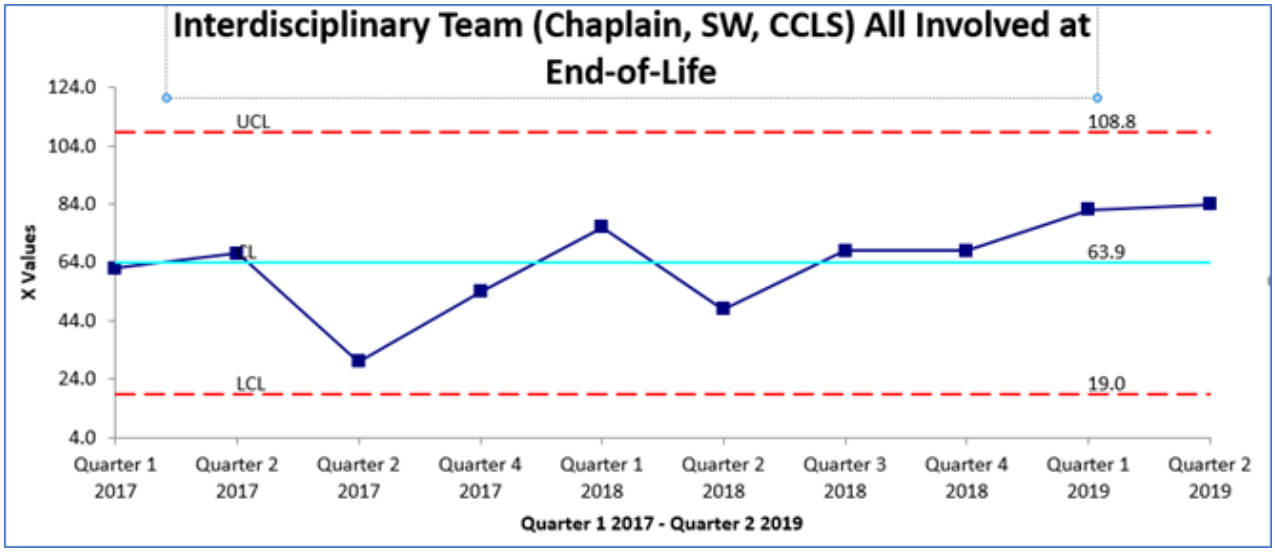
1. Dot phrase developed 6/2017
2. Screens added to consult note template 8/28/2017
3. Note template updated 10/31/2017
4. Reviewed data with team and with individuals. Reminder at weekly meetings 12/1/2017
5. Reminder at Faculty meeting 12/2018
6. Email reminder 10/2019



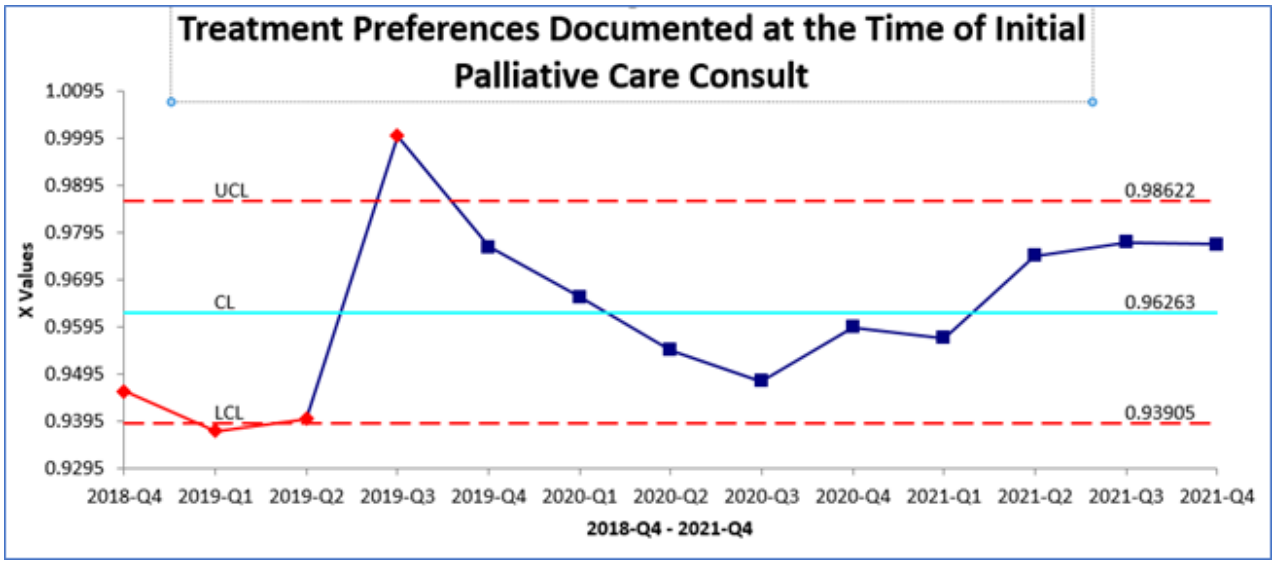
1. Dot phrase developed 6/2017
2. Screens added to consult note template 8/28/2017
3. Note template updated 10/31/2017
4. Reviewed data with team and with individuals. Reminder at weekly meetings 12/1/2017



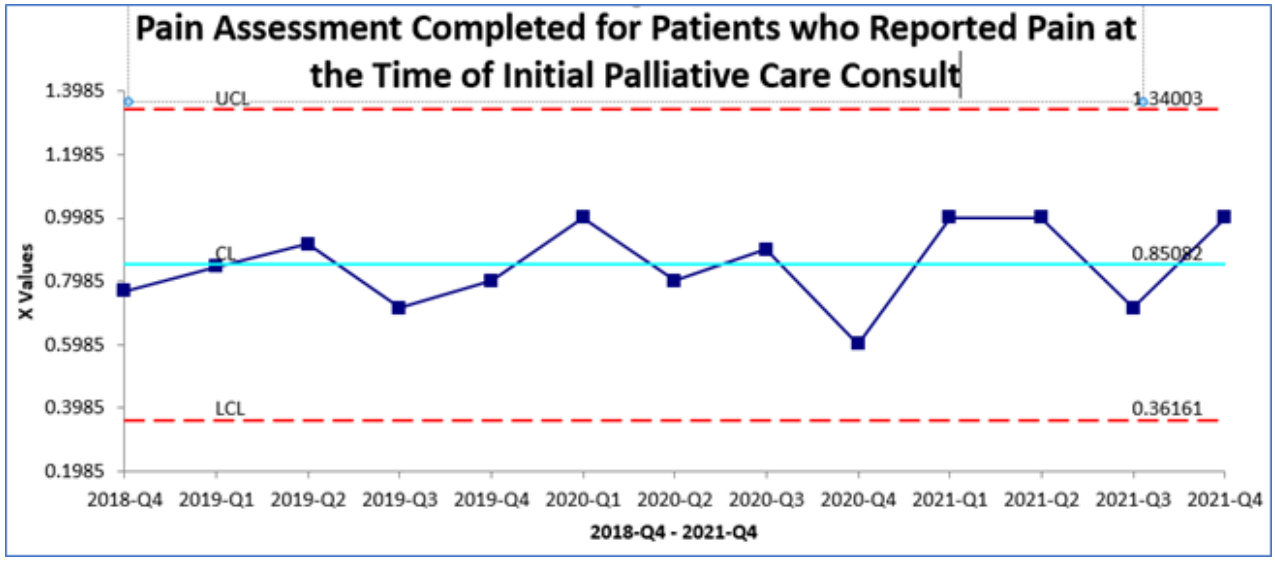
1. Letter template added to EOL navigator 8/2017
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 9/2017
3. Email reminder to off-service attending. Discussion at faculty meeting and signout 3/2018
4. Email reminder to off-service attending 8/2018
5. Email reminder to off-service attending. Discussion at Faculty Meeting 10/2018
6. Administrative support with letters for live discharges 12/2018



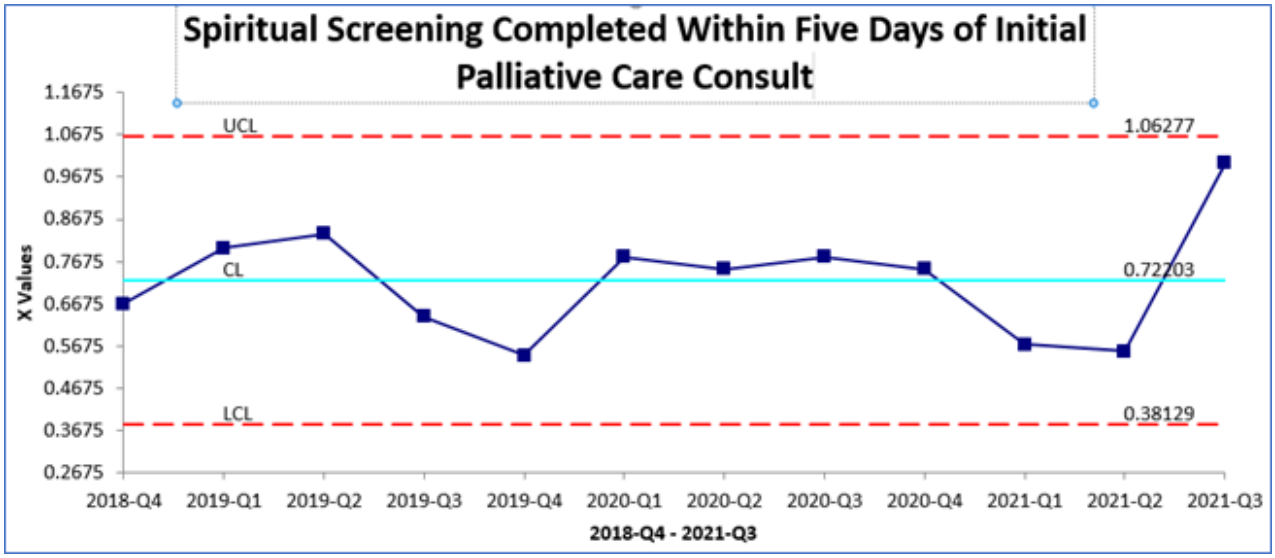
1. Needs assessment conducted to identify gaps in care at end of life 1/2017
2. Bereavement checklist created in paper form 10/2017
3. Bereavement checklist added to EOL Navigator 9/2018



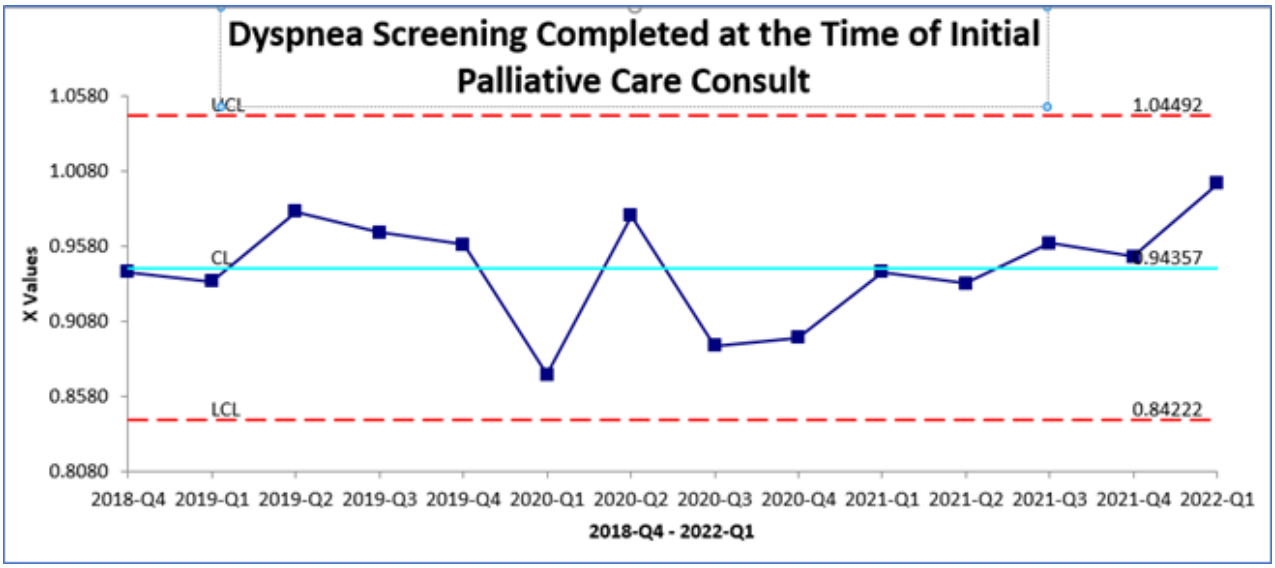
1. Treatment preferences added as a non-editable SmartList 10/2018
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 1/2019
3. Feedback received that documenting in non-editable section is cumbersome and time consuming. Added editable section to expand on details of individual treatment preferences. 4/2019
4. Review at Faculty Meeting 8/2020



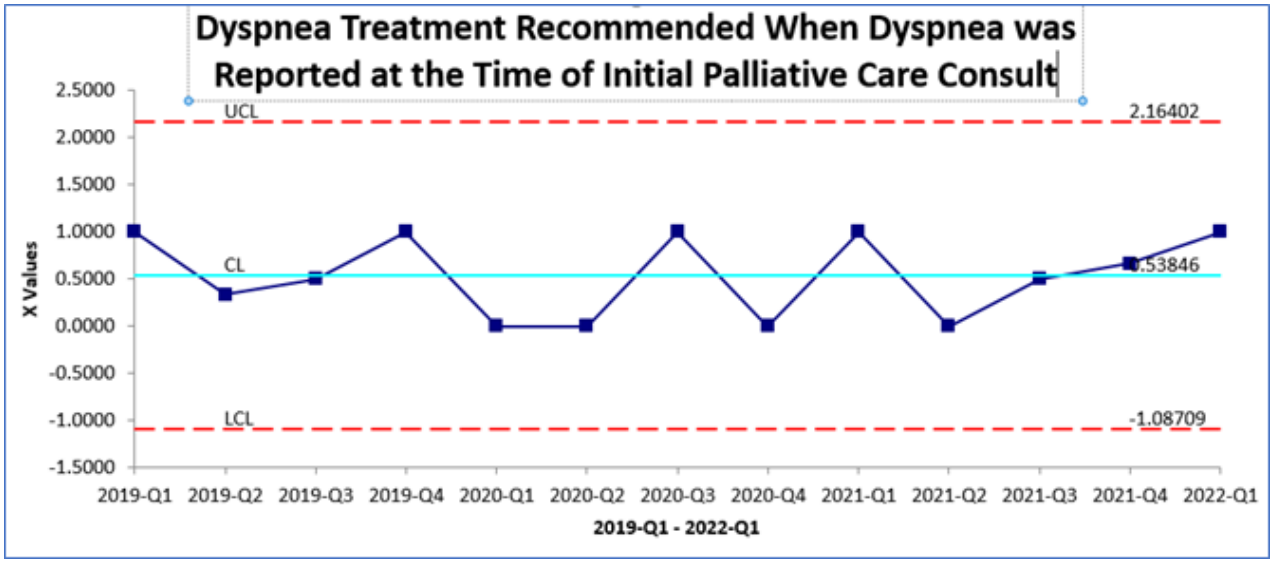
1. Pain Assessment added as a non-editable SmartList 10/2018
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 1/2019
3. Feedback received that documenting in non-editable section is cumbersome and time consuming. It is also at times clinically irrelevant or inappropriate to document in patients who are intubated, sedated or nonverbal. Added editable section to expand on details of pain assessment. 8/2019
4. Email reminders to team. Review at Faculty Meeting 10/2020



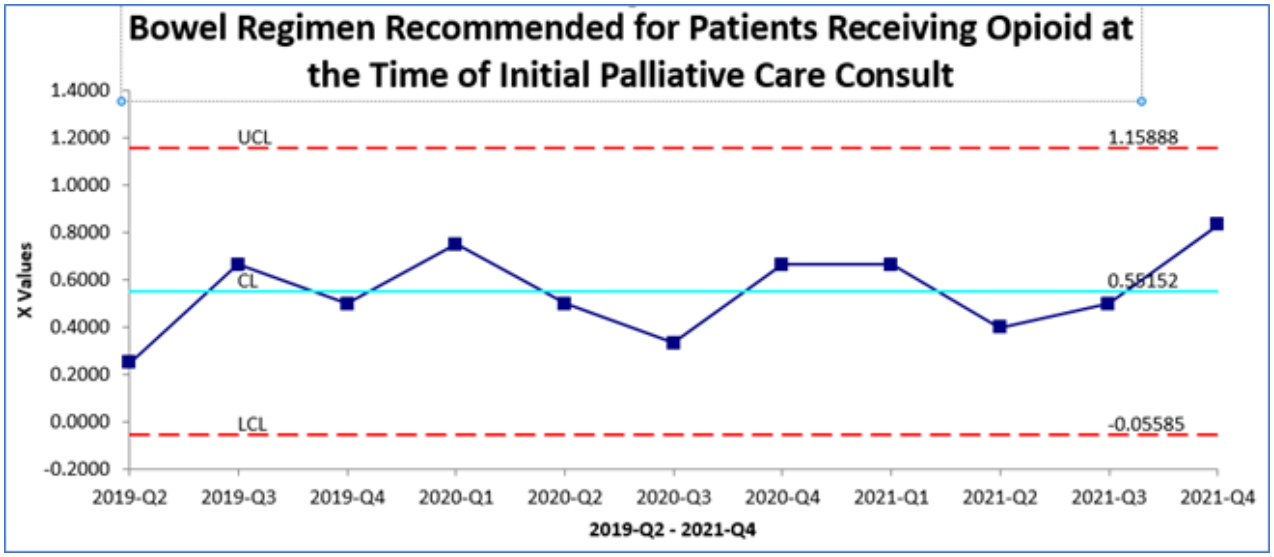
1. Spiritual Screening questions as a non-editable SmartList 10/2018
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 1/2019
3. Feedback received that documenting in non-editable section is cumbersome and time consuming. Added editable section 10/2019
4. Implemented a slogan for Spiritual Screens (Asking about Strength, Support, Spirituality) and a cartoon of our own Chaplain with suggestions on how to ask spirituality faith based questions. Reminders twice weekly at team meetings. Posters put up in the office. 6/2021



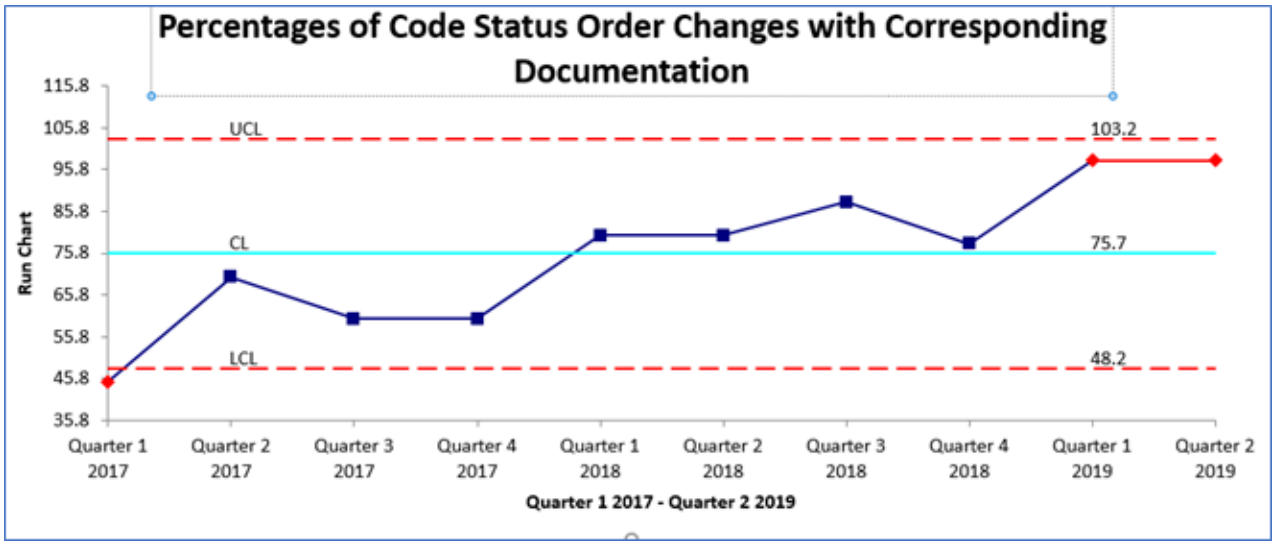
1. Dyspnea screens added as a non-editable SmartList 10/2018
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 1/2019
3. Feedback received that documenting in non-editable section is cumbersome and time consuming. Added editable section 4/2019
4. Emailed reminders to team. Review data at Faculty Meeting 1/2020



1. Dyspnea Treatment options added as a non-editable SmartList 1/2019
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 4/2019
3. Feedback received that documenting in non-editable section is cumbersome and time consuming. Added editable section to expand on details of individual dyspnea treatment recommendations, including non-pharmacologic modalities. 7/2019
4. Emailed team reminders. Review at Faculty Meeting 4/2020



1. Cascading SmartList regarding opioid administration and bowel regimen was added to note template 4/2019
2. Reviewed Data with team and with individuals. Reminder at weekly meeting 7/2019
3. Feedback received that the way the question was worded was confusing. Edited the prompt per team suggestions. 10/2019
4. Emailed reminders. Review at Faculty Meeting 8/2020



1. New order bundle created (see snapshot) 3/2017
2. DNR note template was introduced. Faculty meeting reminders throughout the entire hospital 10/2017
3. Implemented a recommended "soft" stop in the DNR order. Before signing the order, provider must click on the calendar indicating the date that the code status note was filled out. 3/2018

Accountability and Driving Resilient Care

We have used our data warehouse to extract data that are loaded daily into the Qlikview dashboard. Providers use performance data to identify any gaps in care and opportunities for improved care delivery.

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