

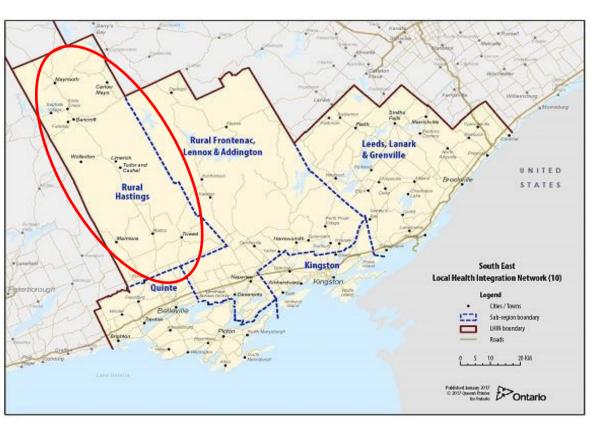
Project: Better Communication within the Circle of Care

Region: Rural Hastings

Executive Sponsor: Dr. Janet Webb

Team Lead: Alicia McCullam

Project Status: Master (Revised April 2019)



South East Regional Palliative Care Network

Problem & Aim Statements: Two sides of the same coin...

Problem Statement

There is a lack of access to time sensitive communication for patients/families and between providers that limits the quality of care patients receive and the efficiency of the care delivered which creates a negative experience for providers, patients and their families.





Aim Statement

We will improve the patient/caregiver experience in receiving timely and accurate communication of relevant information at end of life. We will increase positive patient/caregiver emotions by 10%. We will improve provider satisfaction with the communication they receive in the circle of care by 10% as measured by positive responses reflected in a survey relating to access and timeliness of pertinent information received. We aim to improve these experiences by March 2019.

Project Scope

Improve communication in the last 90 days of life between primary care, SE H&CC Care Coordinators, front line staff, community support services and hospice

Project Team

Executive Sponsor: Dr. Janet Webb

Team Lead: Alicia McCullam

Other Team Members:

Tammy Davis (QHC North Hastings Manager of Patient Services), Emily Rashotte (GCHC Director of Primary Care), Melissa Cousins (SE LHIN HCC Palliative Care Coordinator), Heidi Griffith (Heart of Hastings Hospice Executive Director), Jim Littlefair (Patient Representative), Lisa Hildebrand (QHC Interim Patient Flow Manager), Deborah Milligan (Manager – Home and Community Care, West Access), Kelly Norris (RN Bayshore Home Health), Cris Fransky (QHC North Hastings Patient Care Leads)

SOUTH EAST REGIONAL PALLIATIVE CARE NETWORK

Title: Better Communication within the Circle of Care Scope/Boundaries: Improve communication in the last 90 days of life between primary care, SE HCC Care Coordinators, front line staff, community support services, hospital, hospice and patient/family. Problem Statement/Reason for Improvement: Team Executive Sponsor: Dr. Janet Webb There is a lack of access to time sensitive communication for patients/families and between providers that limits the quality of care patients receive and the efficiency of the care delivered which created Team Lead/Process Owner: Alicia McCullam a negative experience for providers, patients and their families. Team Members: Dr. Janet Webb (Co-Chair), Alicia McCullam (RHHL Project Manager), Tammy Davis (QHC North Hastings Manager of Patient Services), Emily Rashotte (GCHC Director of Primary Care), Melissa Cousins (SE LHIN HCC Palliative Care Coordinator), Heidi Griffith (Heart of Hastings Hospice Executive Director), Jim Littlefair (Patient Representative), Lisa Hildebrand (QHC Interim Patient Flow Manager), Deborah Milligan (Manager – Home and Community Care, West Access)

Aim Statement:

We will improve the patient/caregiver experience in receiving timely and accurate communication of relevant information at the end of life. We will increase positive patient/caregiver responses by 10%. We will improve provider satisfaction with the communication they receive in the circle of care by 10% as measured by survey data. We aim to improve these experiences by March 2019.

Outcome Measure(s)

% of caregivers who indicated they had a positive experience in timing of receiving relevant information.

% of caregivers who indicated they had a positive experience with receiving enough information to make decisions.

% of providers who indicated they received communication with relevant information in a timely manner.

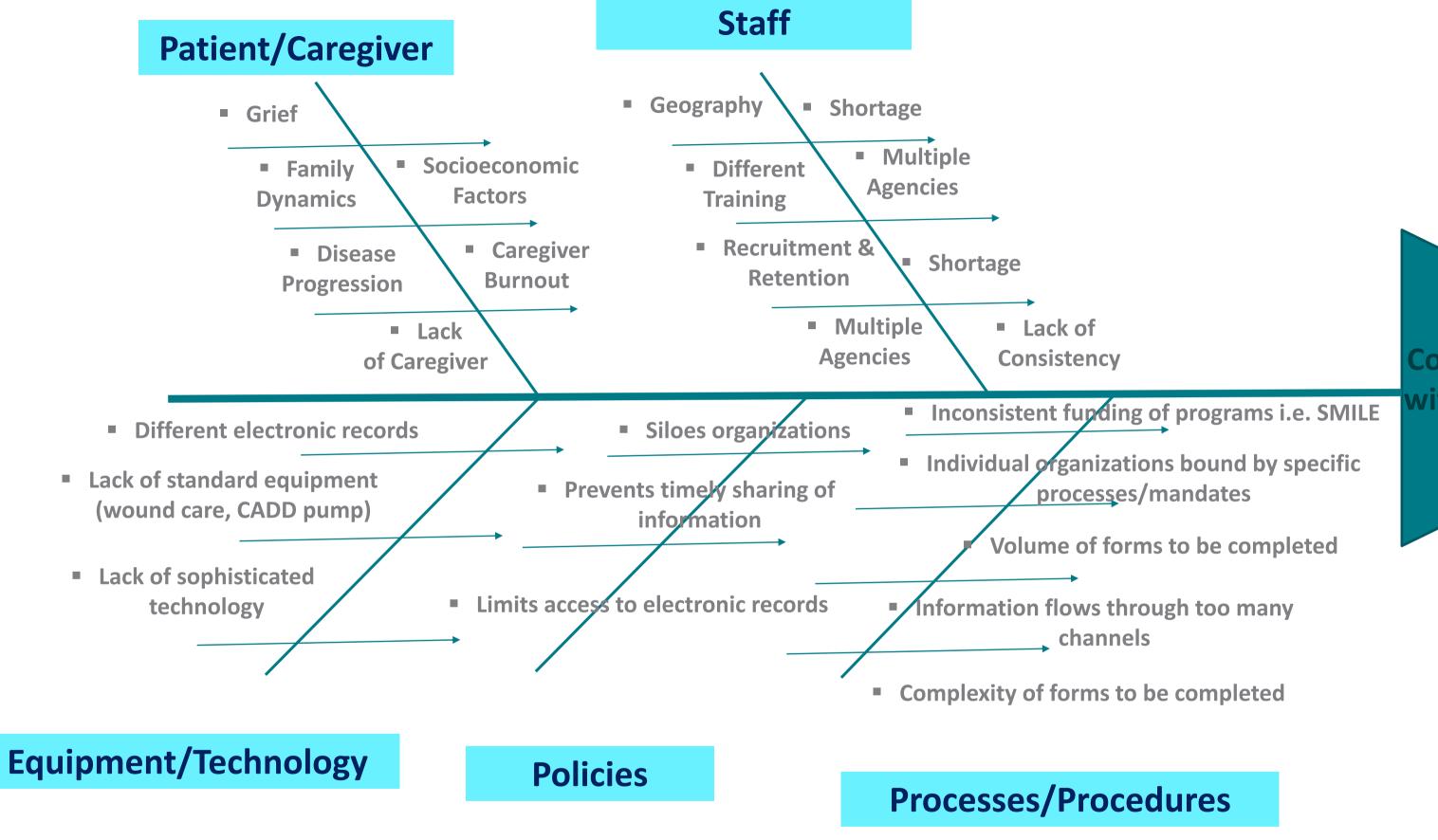
% of providers who indicated timely access to relevant information increased their ability to make time sensitive decisions.

Root Cause Tools Used

- ✓ Fishbone diagram
- √5 Why's
- ✓ Health Care Provider Survey feedback (n=36)
- ✓ Experience Based Design Interviews (10 caregivers, 10 health care providers)

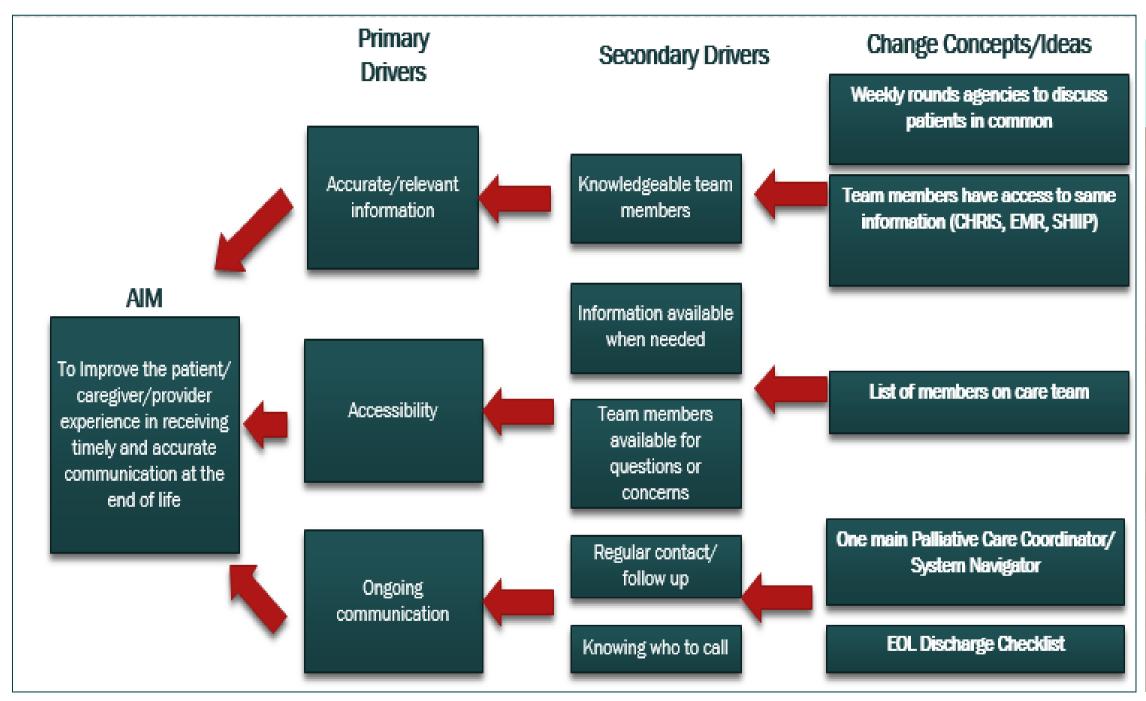
Root Causes:

- -Informal relationships
- -Inconsistency in providers
- -Do not know who is on the 'team'
- -No common tool to communicate
- -Too many providers involved
- -Information flowing through too many channels
- -Training/competency

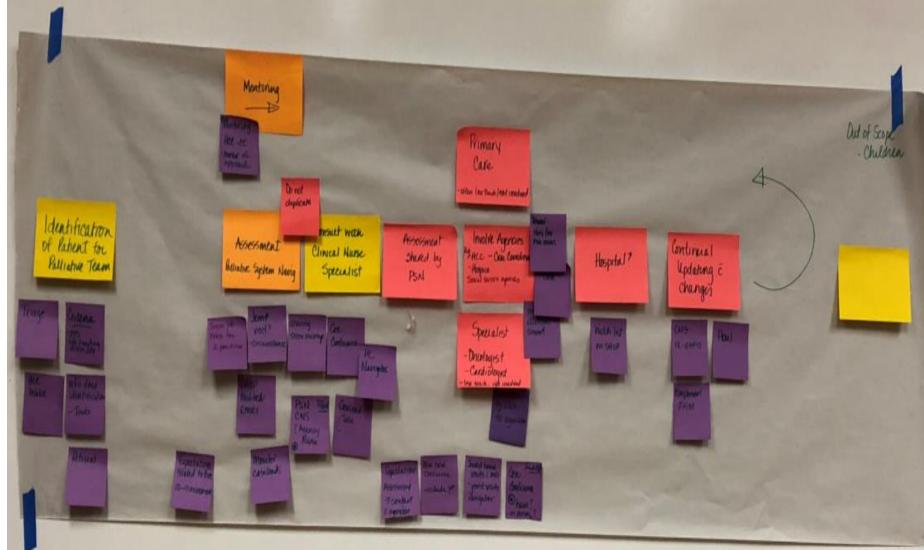


Better
Communication
within the Circle
of Care

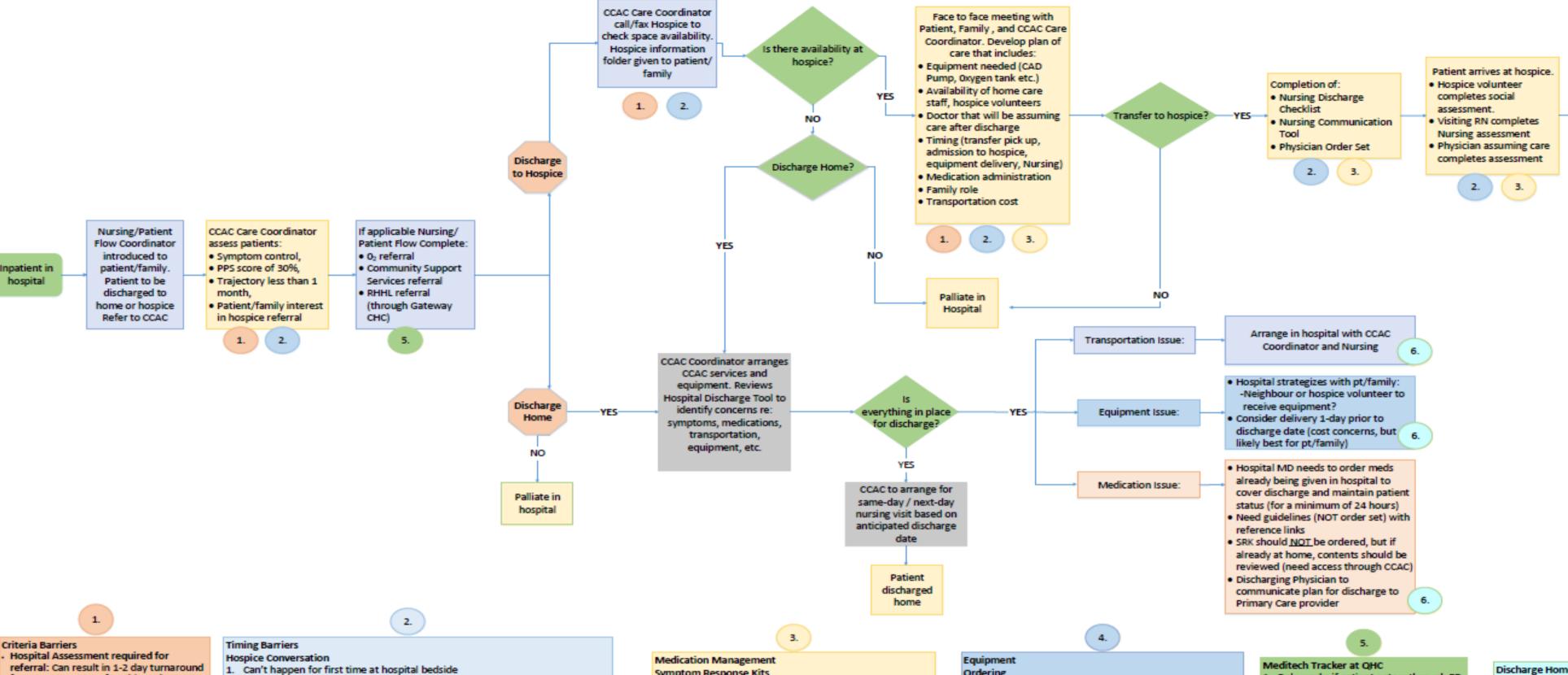
Generation of Change Ideas: Driver Diagram



Mapping ideal future state for communication within the circle of care to identify tests of change



RHHL Transition in Care: Hospital to Hospice or Home Process Map



- for assessment to referral (may be too late to transfer by then)
- PPS of 30% or less: Sometimes arriving too late from hospital, but if too early safety risks at hospice increase related to transfers/ambulation
- Family Education: want patient to stay on Sills 5
- 2. ER doctors not versed in EOLPC assessments, language, etc.
- 3. Family role at hospice needs to be dearly defined
- Day of the week same day admits very difficult, Fridays take ++ pre-planning to coordinate.
- 5. ++ Paperwork required, phone/multiple faxes to different organizations, lack of consistent referral process between sites

Transfer of Care

- Need MD to assume care at hospice
- 2. Up to date Rx list
- 3. CADD pump switch over (return to QHC)

Transportation to Hospice

- 1. Timing of transfer challenging/ who transfers (may need multiple vehicles)
- Family incurs cost (min \$85, or \$165 from BGH to Hastings)

Arrival at Hospice

- 1. CCAC nurse must be present at intake, not always easy to line up arrival with RN availability
- 2. Equipment must be present for intake
- 3. Need additional professional support for first 24h (to give family time to

Symptom Response Kits

- Patient specific QHC told <u>not</u> to order for clients due
- 2. Kits can be ordered by hospice MD, but also result in wastage. Challenges with storage/disposal of narcotics?
- 3. Do not arrive until next business day

Family Administering Meds

- Volunteers currently not able to administer any meds
- 2. Family need to be trained and comfortable in administering meds

CADD Pumps

- Hospital and Community pumps not interchangeable.
- Hospital not supposed to allow pumps out into
- 3. Takes 24 h for meds to arrive for pump if ordered as "urgent or same day" can arrive within 4 hours, but @ 3-10x normal cost.

Ordering

- CCAC Care Coordinator cannot order equipment with wheels without Physiotherapist/Occupational Therapist recommendation
- 2. Same day order increases cost for delivery

Receiving Equipment

- 1. Patient or family must be present to receive delivery
- 2. Drop off time dependent on delivery route
- 3. Drop off may not be same day as discharge
- 4. Education on equipment use not provided in the home

- 1. Only works if patient enters through ED
- 2. Follows patients to floor
- 3. Can see CCAC services (OT/PT/Nrsg) are we able to SRK?
- 4. QHC working on getting RHHL and QHL as well as Palliative NP, etc. added to tracker.

Discharge Home Checklist Support seamless discharge home

6.

Hospice &

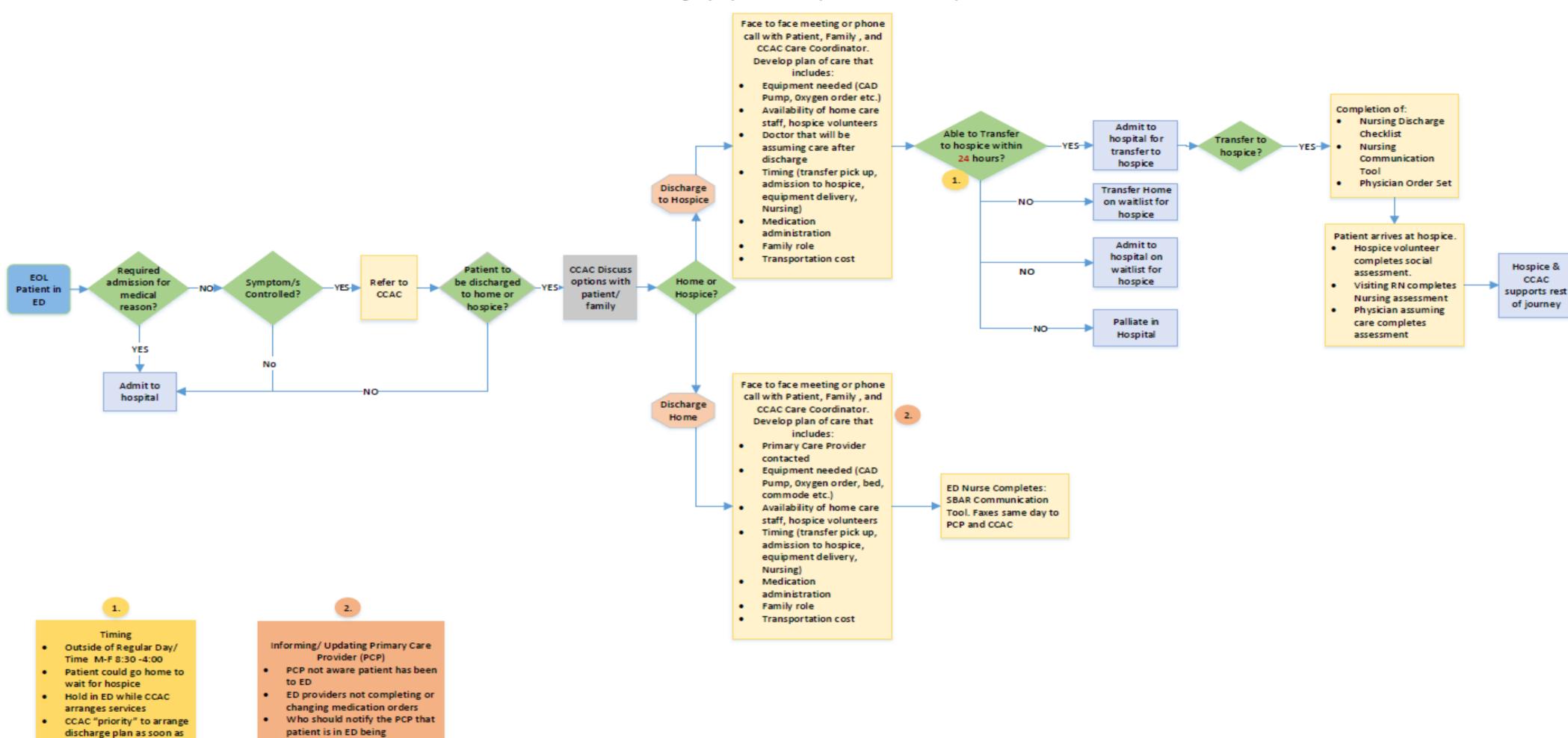
CCAC

supports rest

of journey

- 1. Transportation Issue
- 2. Equipment Issue
- 3. Medication Issue

RHHL Transition in Care: Emergency Department to Hospice or Home Process Map



discharged?

discharge

Discharging provider to call PCP

CCAC CC call PCP - CCAC not

always aware of hospital visit

Hospital Palliative NP - could

they facilitate orders and discharge plan with PCP?

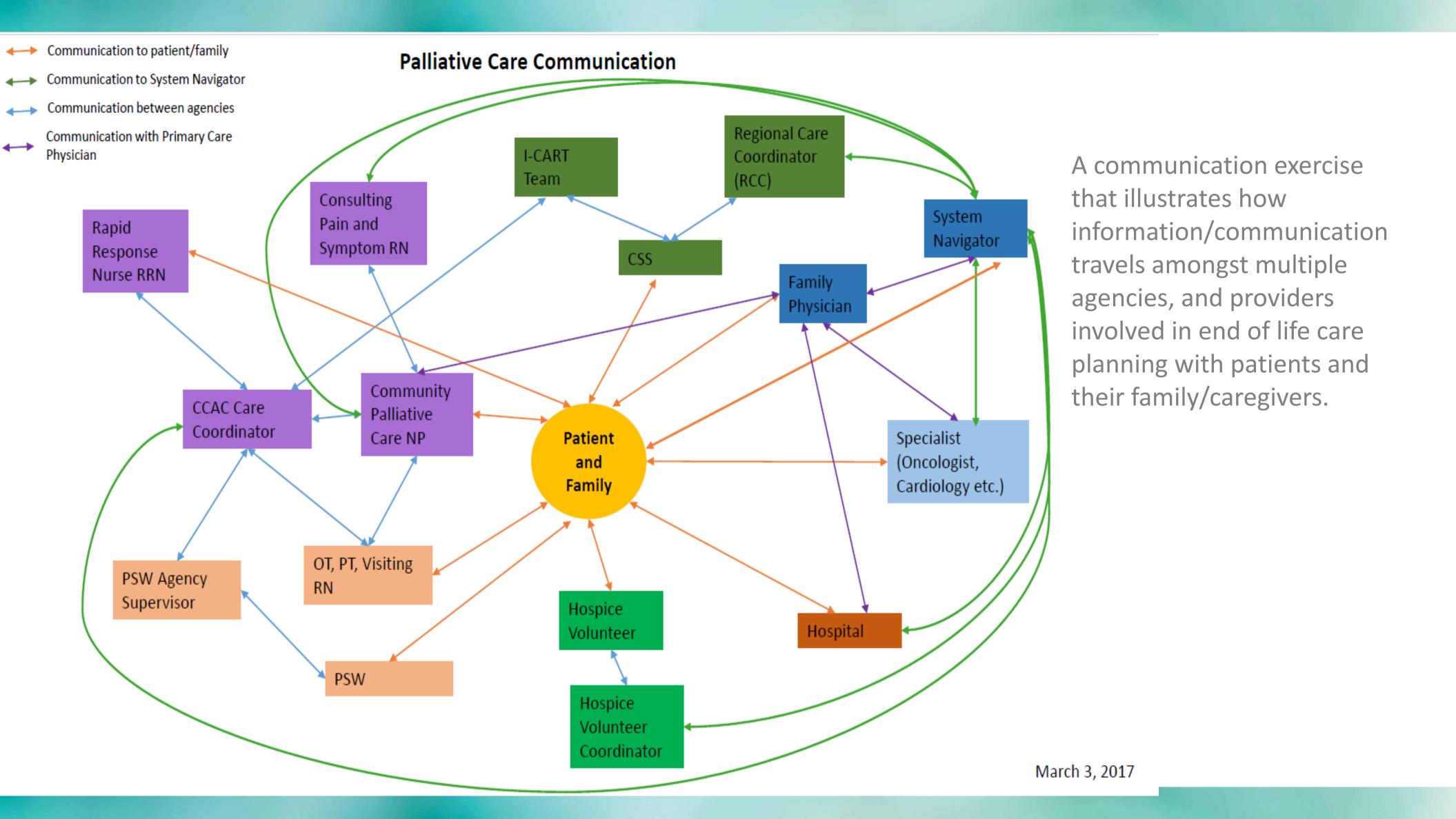
po ssible

Friday at noon deadline -

CCAC pre plan for

patient until then

discharge Monday, hospital could "hold"



Survey and Experience Based Design for provider and caregiver feedback



Provider Survey Questions

Please answer these questions based on your experiences supporting your patients at the end of life

1.	Other:			e, Physician, System Navigator)	
2.	How many years have you worked in your role? ☐ 1-3 years ☐ 4-6 years ☐ 7-11 years ☐ 12+				
3.	When supporting your patients at the end of life, do you feel you received enough information to support your patient, from the organizations/front line staff listed below? Please check all that apply.				
	□Primary care □Nurses □ Hospice	□Nursing agencies □PSWs □Other, please specify_	☐Hospital ☐Special		
	If you did not receive en	nough information to supp	oort your patient, what inf	formation was missing?	
4.	Is there a specific time in transitions of care for your patients where you feel the communication/information you need to support your patient was not provided or not provided in a timely manner? Please check all that apply below.				
	☐ Hospital to home ☐Hospital to Hospice		unity Communit		
5.	Are you able to access the information you need to support your patient when you need the information Always Some of the time Seldom Never Comments:				
6.	Is the information you receive relevant to support your patient? ☐ Always ☐ Some of the time ☐ Seldom ☐ Never Comments:				
7.	□Phone call □Fa	low do you receive most information, please check all that apply □Phone call □Fax □Electronically (patient record system) □In person □Other, please specify			
8.	Is this your preferred method of receiving information? Always Some of the time Seldom Never How would you prefer to receive information?				
9.			s of receiving relevant info	ormation in a timely manner to	
10.			ms of receiving relevant in	formation in a timely manner	

Experience Based Design for Providers (End of Life)

- What is your role?
- 2. How long have you been in your role?
- 3. Have you had any palliative care training? If so, what training have you received?
- 4. Can you share with me an experience that stands out where things went really well?
- 5. Can you share with me an experience where things really didn't go so well?
- 6. How is information communicated to you for the client you are supporting at end of life?
- 7. Could you describe your experiences in receiving the information that is required to support your client at the end of life when the information is needed?
- 8. Could you describe your experience in not receiving the information you need to support your client at the end of life in a timely manner?
- 9. Do you ever worry you don't have all of the information you need to support your clients at the end of life? What information is required?
- 10. Related to transitions in care
 - Can you describe how you receive information during those transitions specifically related to the timing of information received
 - b. Can you describe the amount of information you receive in terms of was it enough to support your client, and was the information relevant?
- 11. As you know, many providers are involved in end of life health care delivery (PSWs, nurses, physicians, etc.); how do you feel the communication works?

Experience Based Design Questions for Caregivers

- 1. Can you tell me about your story from start to finish?
- 2. Can you talk about the different transitions in care you experienced as a caregiver?
- 3. What transitions seemed the most difficult?
 - a. Can you describe how you were feeling?
- 4. How did you receive the communication you needed to guide your decision making in supporting your loved one?
- 5. What information did you receive that allowed you to support your loved one?
- 6. What information could have been helpful but was not received?
- 7. Can you give an example of when you felt you received the information at the right time?
- 8. Can you give me an example of when you needed more information or communication but it was not communicated?
- 9. As many providers are involved in supporting a patient at the end of life, how do you feel the care team provided the same message?
- 10. What is the most important message you want to share?
- 11. Any additional insights/perspective to share?

Qualitative Analysis of *Caregiver Experience* Based Co-Design Interviews (n=10)

	Patient/Caregiver Received Relevant Information	Patient/Caregiver Received Accurate Information	Patient/Caregiver Received Timely Information	Patient/Caregiver had Access to Information
Burnout Frustrated	How to get help at end of life No one talked about what was going on	Not told what to do with supplies after death	Early end of life conversations did not occur	Couldn't get an appoinment with
Upset	No one brought up palliative On a	Prognosis very wrong-gave 2 years, passed	Coordinator arrived too late	physician
Disappointed Angry	care option scale of 1-10, how sad	in 4 months Providers not talking to eachother or us;	No one involved until very end of life	chasing physicians-no answers
Lost	Asking questions that would not help with care	are we continuing with treatment or not?	Trying to get bed/equipment	Home equipment services-do not know how to get
Confused Unsupported	Care got disjointed in hospital-no one would talk to us or give us answers	Providers afraid of talking about death Did they have to do the surgery? Could it	Communication from agencies did not occur, had to phone	Inconsistent messages from
Overwhelmed	Different Doctor everyday-didn't know which one to talk to	have been avoided?	around for information	providers
Difficult Tiring	Did not know what my options were of our	Did a referral get sent to H&CC? what is the plan?	PSW not showing up or changing times last minute-went on for months	Home care did not come until end
Annoyed Bitter	to support my love one at home	No It would have helped if I had a plan, "if this	Personal care came too late!	Delays in getting services started
Anxious Worried	No teaching on what to expect, symptom management-they were 45 minutes away	patient/caregiver happens, I could do this"	PSW cancelled-regularly	Couldn't get clear answers from
Helpless Panic	Case manager did not understand how to interact with palliation	Frequent ED and Emerge visits-lack of support and	Asking for more help	anyone; we just seemed to be lost
Scared Guilty	Searching for information	communication		
Alone	No prognosis or treatment information provided	Inappropriate hospital discharge without nursing scheduled, meds, IV		
Exhausted Supported	Care Coordinator listened and advocated for rapid access to urgent response team		Care Coordinator addressed concerns promptly	Physician at hospice had supportive end of life conversations
Safe	Hospice answered questions-took time	Information on medications provided	Regular communication from case manager	Physician provided all information
Good			Equipment arrived promptly when ordered	Calling nurse and PSW
Relieved Comfortable	Good facilitation of information for transfer	Physician home visits-kept informed and answers all questions	Referral to Specialist was quick after	H&CC Coordinator sat with family
Confident			diagnosis	Care Coordinator was available and
Grateful			PSW reliable-called to say when they were coming, what to expect	would return calls Care team approach
Нарру				care team approach

SOUTH EAST REGIONAL PALLIATIVE CARE NETWORK

Qualitative Analysis of *Provider Experience* Based Co-Design Interviews (n=10)

	Provider Received Relevant Information	Provider Received Accurate Information	Provider Received Timely Information	Provider had Access to Information
	Can be difficult to try to navigate the	Wrong diagnosis	Some referrals are received too late, impacts patient's quality of life Do not know when patient is being discharged Do not receive hospital information regularly when patient is admitted.lt No information	Takes effort to find out who is the nursing agency and the nurse involved with the patient
Frustrated	hsopital once the patient goes in; do not know the patient is in or for what reason	PPS		
Disappointed		Updates from home care		Information is lost once they enter hospital
Difficult	Regular information does not flow	Incomplete information		Care coordinator to physician communication
Confused	Do not have time to search for information	Inconsistent information from multiple providers		No information on outcome of
Confused	Physician's do not call	Received completely wrong information and had to go searching for correct information	then is not timely	situations
Tiring	Information is not being disseminated		Inings fall through at discharge	
Annoyed Worried	Nursing only seeing the patient twice a month, not receiving a current report	Did not recognize/pick up on issues that were going wrong	Many obstacles for receiving information in a timely manner Fax versus real time Things are not	
Helpless	Rarely hear of patient dying-have to find out in the obituaries	One single person needs to watch over all of the information	Hospital report goes to LHIN head office, then into the system, could going well, the report is time sensitive and then it arrives in 3 or 4 days	
Exhausting Disheartening	No feedback when I have implemented evidence based guidelines-was it effective?	or it falls apart	be 5 days before seeing it Hospice not admitting on Friday unless everything is ready the	
	Lack of case conferencing		day before, short turn around time to have everything ready	
Supported	Case conferencing	Phone calls from physicians	Some nurses provide timely updates with a phone call	Relationship with care coordinators
Informed	Meeting visiting nurses at	Under the Section Notice of		Ease of accessing team members when you know
Good	patient's home	Updates from System Navigator	Relationship with providers is well established so when I call they will speak to me	
Relieved	Relationship with team members and known in the community with physicians	Updates from hospice		When you know who is on the team and have
Confident Grateful	Updates from family/caregiver	Updates from Palliative Care Coordinator		established relationships over time, the information can flow much easier
Нарру	System Navigator involvement			

SOUTH EAST REGIONAL PALLIATIVE CARE NETWORK

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Caregiver Impact Statements





- •The hospice people were great and transitioning into the hospice was great
- •I was so grateful for the Doctor at hospice
- •One care coordinator was remarkable and she took the time and listened to everything I had to say
- •I didn't have to go chasing, she (care coordinator) did that.
- •Those final pieces were comforting, that is 24-36 hours of compassion and support.
- •It takes a team of people to provide that kind of care
- •She talked to both of us, she treated us with respect
- •Hospice made it easier for me, to love my mother opposed to being there with all the stress
- •Hospice allowed us to support our loved one while they supported us and that provided peace

- •It can be described as a battle rather instead of a moment to grieve
- •I feel like I am losing my sensation, is that what dying is like? (Patient) .Supportive conversations, education, what to expect are not occurring
- •You don't realize you're burning out until it happens
- •They were discharging her regardless, where do you want us to send her; in other words we don't want her here
- •The room (hospital) was small and hot, we had to go begging for ice chips and water
- •I was a basket case; I didn't know what to do
- •Couldn't get clear answers from anyone, we just seemed to be lost
- •This felt like I am always battling-for any kind of help
- •Getting access to palliative care and that transition from hospital to palliative care gets a little rough because it's a lot to put on a person when their spouse is dying and sometimes they are not equipped to make the best decisions.
- Hugely frustrating
- •When they say they can provide things, they need to be held accountable and ready at the times stated.
- •When you are reaching out to ask for help and then told you don't need it-it is devastating.
- •Final times of life deserve better

Provider Impact Statements



- •The right people in the role can make the difference
- Hospice communication is streamlined and effective
- •Communication is easier between patient and care team as point person is established
- •Small team allows close working relationships with professional agencies
- •Sharing of information requires building relationships with key players
- Communication is often relationship based
- •Relationships drive best practice
- •Most of the time I can get the information—if I have a close relationship with them, they call me
- Nurse may pass but the PSW has the information.
- •I make sure that the PSW know they are valuable. They may not even realize the information they hold.

- •In healthcare, we don't talk to each other; we fill out forms...that are mandated...that no one looks at.
- •As a healthcare provider, I was disappointed, we could do it so much better
- •Too many loop holes to jump through, silos to jump through, people hiding behind privacy laws preventing flow of communication
- Guarding information
- •They need to have one single person who is watching over all of the pieces of care, it all falls apart.
- •When you get to palliation there seems to be this gap between everything from physicians, to Home and Community Care, Hospital, Hospice or whatever. Every single one of those situations families are getting irate or giving up.
- •So many things get missed; it is unbelievable; these are significant health consequences
- •There are so many referrals that someone can say 'hey, something is going on' and you shouldn't have to wait for critical and crisis situations before catching-you can't catch 100%-many instances, yes.
- •You know the system, until you are living in it, then you realize how broken it can be.
- Labour is required to get information
- •The norm is frustrating, the accessing and long lags in between; delays and duplications. Totally avoidable.
- Person dependent (if communication is timely)

What was Important to Patient/Caregiver

Opportunity to express their wishes and have them be heard and respected

Receive quality care at end of life because only 1-2 nurses providing care were involved

Have honest conversations about death

Receive communication, updates; someone talk to us

Resources-too late

Know what the options are if I take my spouse home vs. hospice? Will I have support?

Someone to listen to our story

Respite hours to support caregiver-not enough

On call hospital physician took the time, sat down listened to the patient's wishes, explained the process of receiving treatment vs. not,

Asked the patient their preferred place of death and facilitated that transfer

To be able to support their loved one without all the stress

To have all the information to make decisions

Receive support and services without battle

To be treated with respect

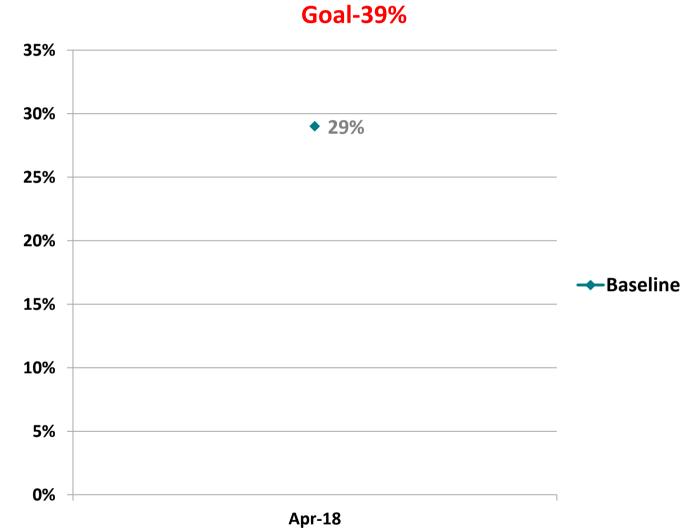


Out of Scope — Additional feedback from provider and caregiver interviews that is out of scope for our project but requires noting

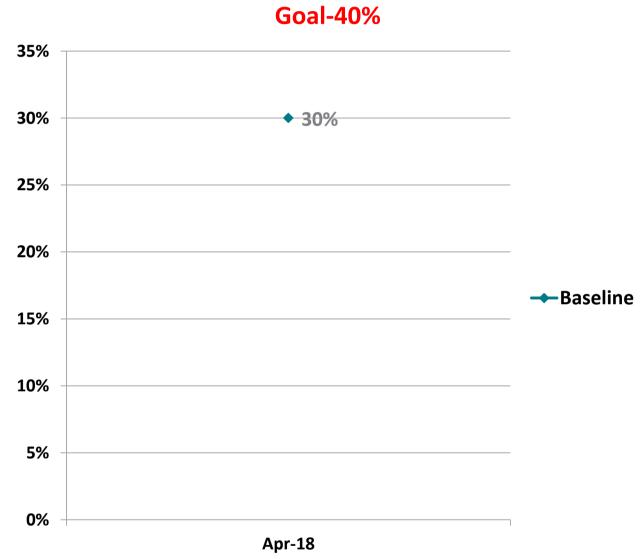
- >Accessing dietician services
- > Financial burdens-could not take time off to provide care, take to appointments, etc.
- **≻**Cost of drugs (some samples)
- > Fee for foot care services (for home visit)
- >Competency (unnecessary treatments, inconsistent information, wrong medications, different levels of care, basic care, etc)
- **➤**Nursing not spending enough time for care
- **▶** Basic care did not happen
- **≻**Staffing issues-no coverage
- **→** Hours for Nursing/PSW needs increasing
- > Eligibility-did not quality for personal care so daughter had to miss school to take care
- **≻**No family support
- >Lifeline not funded (patient had to be left home all day unsupported as caregiver had no choice but to work. Patient would be falling constantly).
- **▶** Coverage of geography for Palliative NP-limited in number of patients can see
- **►**Inconsistent excellence in nursing and PSW staff
- ➤ Education is not covered nor is time to upgrade skills, or cannot attend due to coverage issues
- **▶**Inexperienced newer PSWs or nursing-inconsistent care
- **≻**Community nurses are not paid well
- **≻**Lack of social work/spiritual support across QHC
- **►** Last minute revoking of DNRs-hospital
- ➤ Geography of agency nurses having to cover (for example: to restart a line)

Run Charts for Outcome Measures

Percentage of caregivers who indicated they had a positive experience receiving relevant information in a timely manner



Percentage of caregivers who indicated they had a positive experience with receiving enough information to make decisions

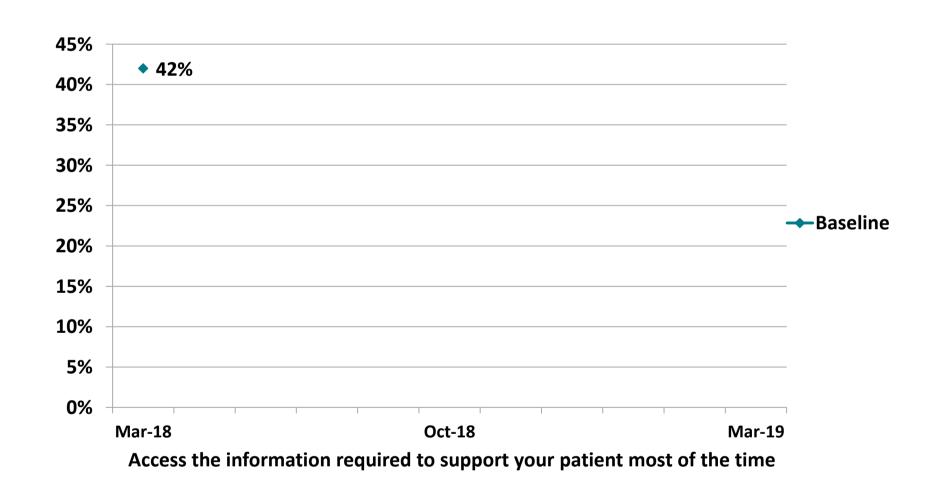


Caregiver responses from Experience Based Design Interviews conducted within the Rural Hastings Sub Region

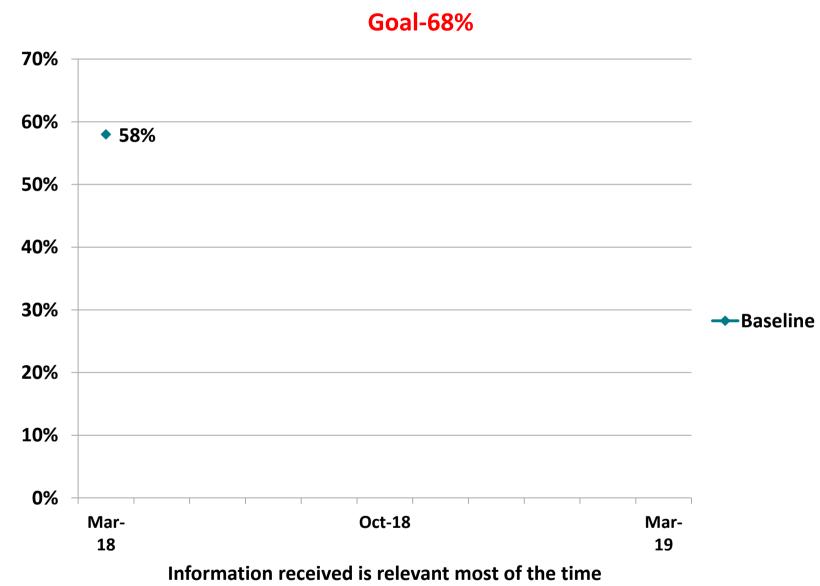
Run Charts for Outcome Measures

Percentage of Providers who answered they were able to access the information needed to support their patient 'most of the time' (n=36)

Goal-52%

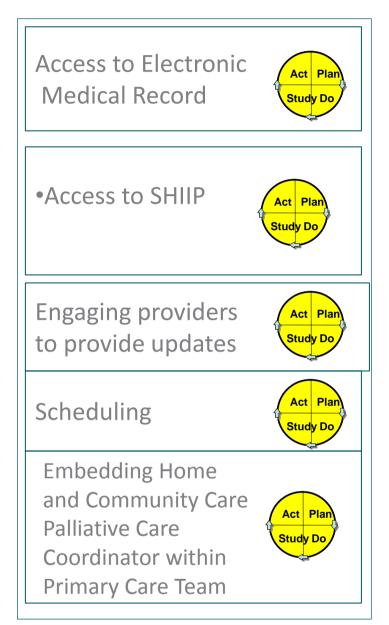


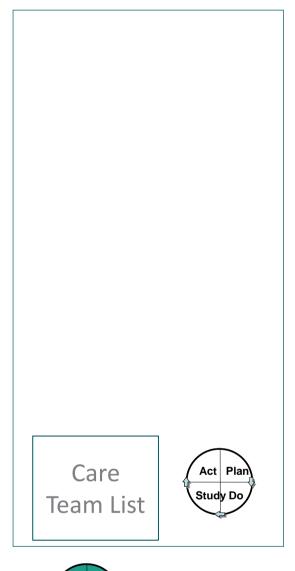
Percentage of Providers who responded the information received was relevant 'most of the time'

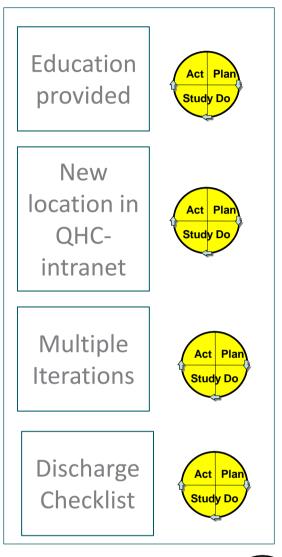


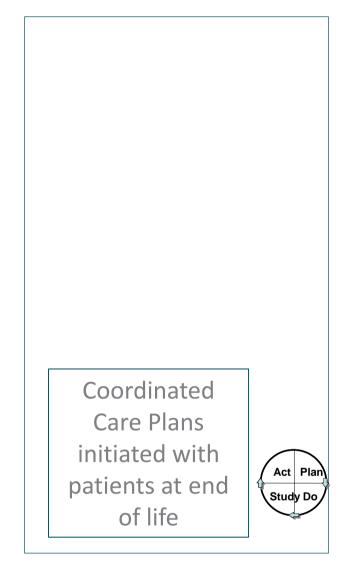
Provider survey responses from completed surveys within the Rural Hastings Sub Region

PDSA Status: Developing/Testing Change Ideas **STATUS**















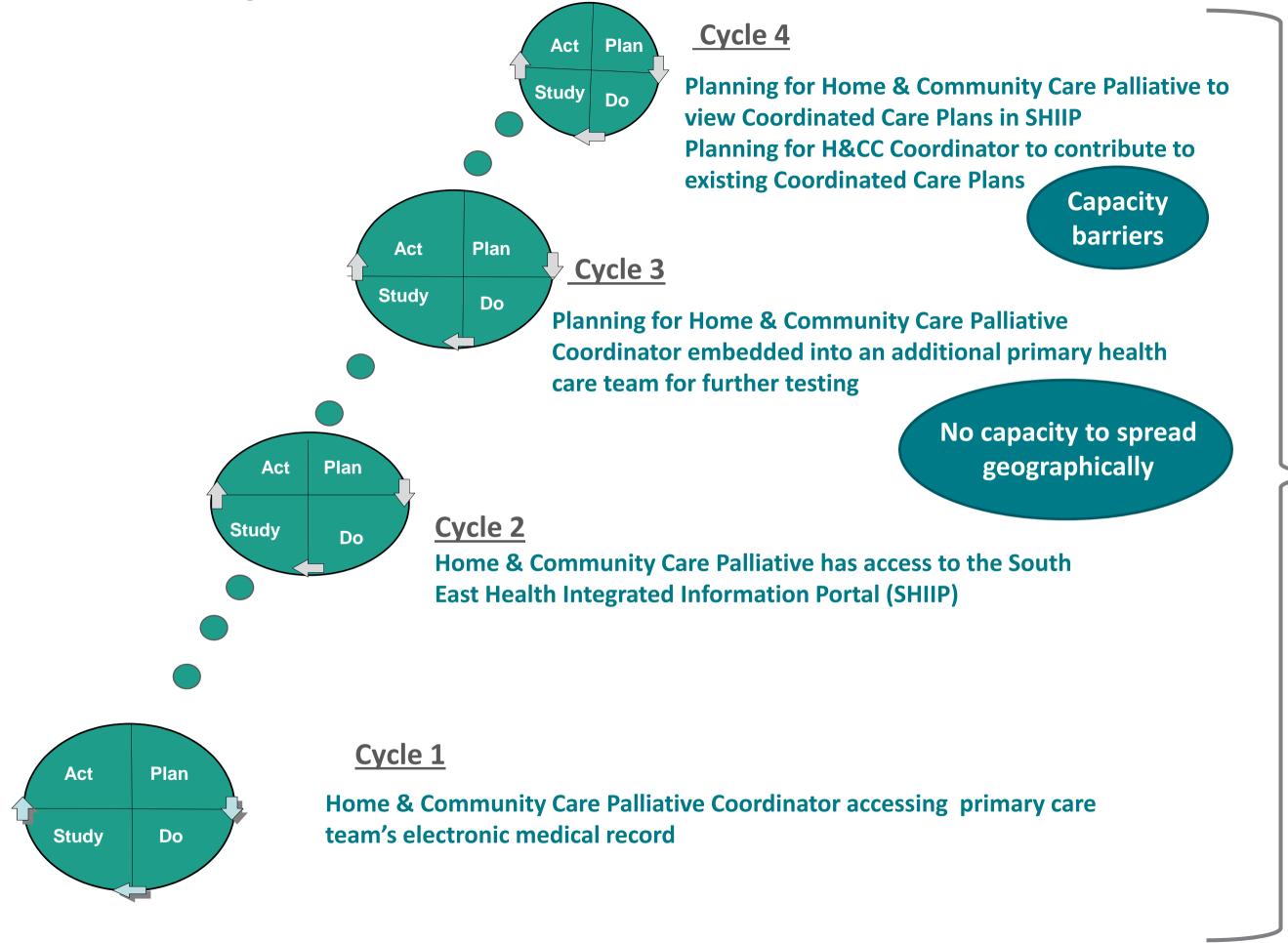
Developmental

Testing

Implementation

	Develop	Test	Implement	Total # Cycles
Summary		8	2	10

PDSA cycles to date for embedded H & CC Palliative Care Coordinator



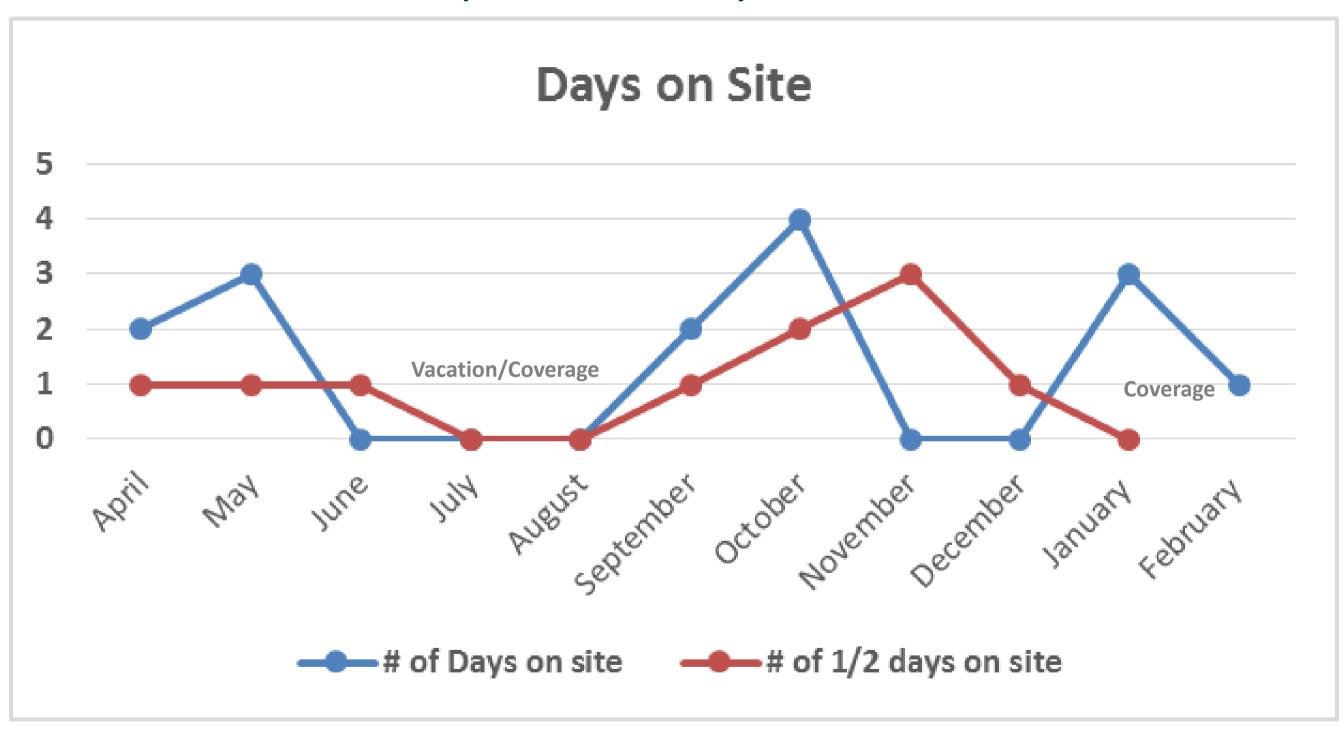
Developmental

Testing

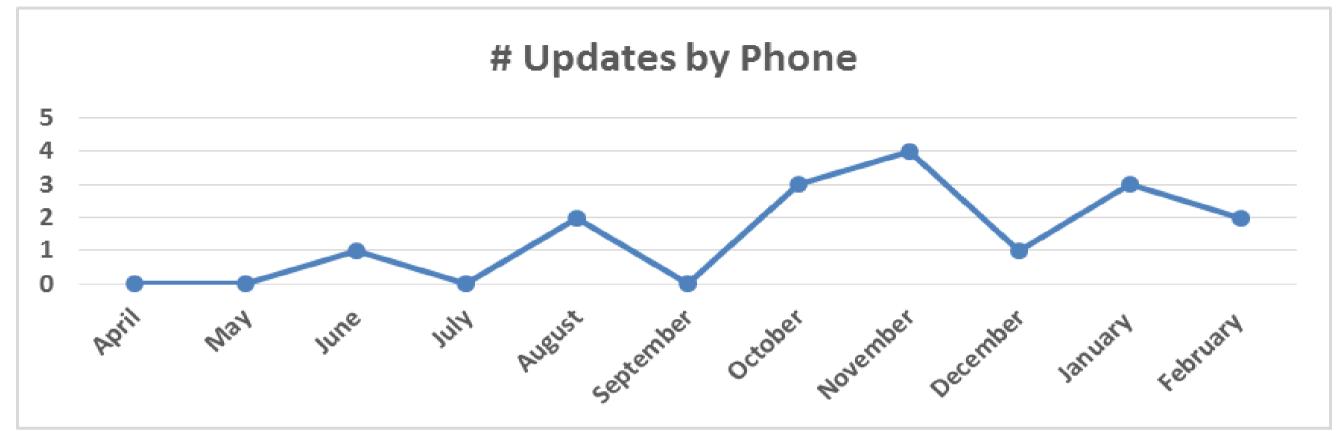
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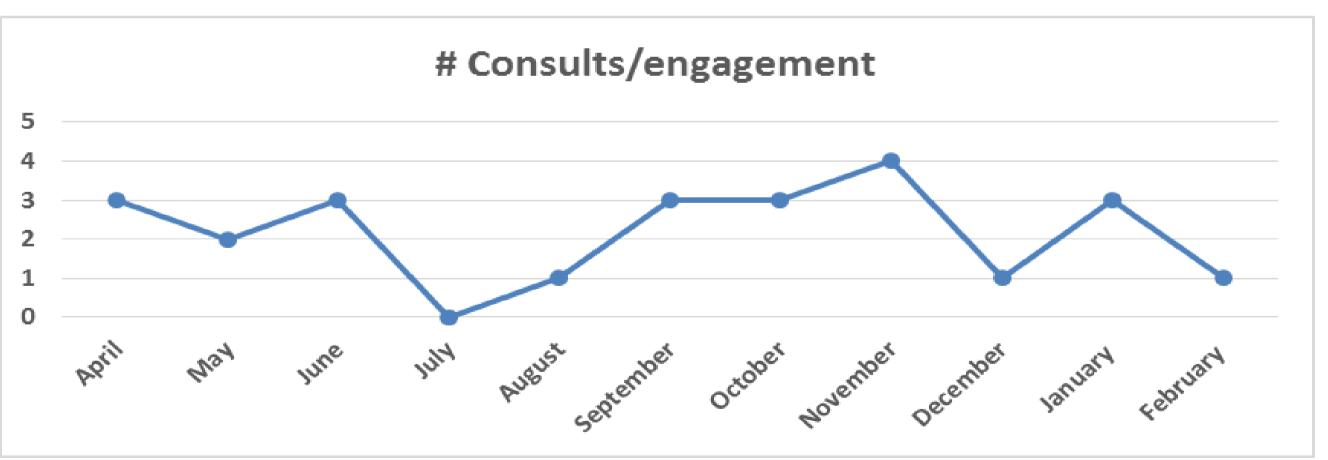
Run Charts for Process Measures

Palliative Care Coordinator April 2018 to February 2019



Palliative Care Coordinator April 2018 to February 2019





Feedback from Primary Care Providers on their Experience with having the H&CC Palliative Care Coordinator on site

When Providers were asked...

"Do you know the Home & Community Care-Palliative Coordinator supporting your patients receiving palliative care?"

100% of providers surveyed responded, 'Yes'

Overall increased satisfaction with the direct access to the Palliative Care Coordinator

"Are you comfortable contacting the Home & Community Palliative Coordinator supporting your patients receiving palliative care?"

100% of providers surveyed responded, 'Yes'

"Do you find it effortless to get a hold of your Home & Community Care Palliative Coordinator supporting your patients receiving palliative care?"

75% of providers responded, 'Yes'

"Is there an ease in accessing the services that the palliative care coordinator delivers (i.e. CADD pump)?"

❖ 50% of providers responded 'Always', 50% responded 'Some of the time'

When asked "what are some of the ways you contact the Palliative Care Coordinator?"

- **E-mail**
- Phone
- **EMR Direct Messaging**
- ***** Fax directly to home and community care

Provider Quote:

"I've found it very
useful to have the
palliative care
coordinator onsite at
our clinic
intermittently."

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Feedback from Palliative Care Coordinator

Successes

- Concept is great
- Able to get information when needed
- Relationships with physicians and NPs is good
- Access to EMR has been helpful
- Knows the primary care providers
- Opportunities to provide and receive updates
- Presence in the office

Barriers

- Geography
- Caseload
- Covering for other Care Coordinators
- Shared office (patient confidentiality for patients not rostered to CHFHT)
- Engaging providers

How does Embedding a Palliative Care Coordinator within the Primary Care Team Improve the Patient/Caregiver Experience?

- ✓ Palliative Care Coordinator informs patient's care team of any changes in status
- ✓ Accessible by members of the patient's care team for consultation, questions, updates
- ✓ Palliative Care Coordinator has access to primary care EMR (history, consultation notes, specialist notes, medication lists, etc.)
- ✓ Palliative Care Coordinator is the conduit between care team members and patient/caregiver
- ✓ Increases patient's confidence in members of their care team
- ✓ Presence in office builds relationship amongst primary care and Palliative Care Coordinator



Accomplishments

- ✓ Embedding Palliative Care Coordinator within CHFHT
- ✓ Discharge checklist (educating front line hospital nurses and hospital managers, increased utilization of the checklist and communication generated because of the checklist, improved transitions in care for patients)
- ✓ Completion of provider surveys and provider and caregiver interviews were valuable to the work of the project.
- ✓ Participation in the RPCN projects
- ✓ Presentation to members of the OPCN
- ✓ Dedicated Team members
- ✓ Continuing to build on relationships in the Rural Hastings Sub Region and beyond

Lessons Learned

Challenges Encountered

Resources for testing change ideas

Additional representation from H & CC, Home Care, Primary Health Care and Hospital would be beneficial

Additional care givers on project team would be ideal

Small scale change

Data collection

Lessons Learned

Factors Enabling Project Progress and Pace

- Dedicated working group members
- Champion Physician as executive sponsor
- •Ruth Dimopoulos, Project Team Leads, Hilary Blair
- Regular touch points
- •RPCN Steering Committee

THANK YOU QUESTIONS??



SOUTH EAST REGIONAL PALLIATIVE CARE NETWORK