Lessons learnt during the introduction of Person Centred Outcome Measures (PCOM) at Marie Curie Hospice, West Midlands

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Outcome Measures in Practice ECHO Network

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Care and support through terminal illness

Background

- Electronic patient record (SystmOne) in place since 2010
- Accepted as a pilot site for the Pilot Palliative Care Data set by Public Health England (PHE) in July 2015
- 6 month period to:
  - Change culture and the language used by staff
  - Configure Systmone for data collection
  - Create reporting tools

Aim

To embed any future dataset within Systmone to ensure that data was captured within standard working practices to enhance patient care as well as improve reporting of patient outcomes.

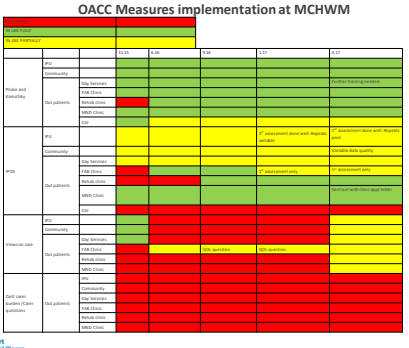
In Summary……

NOT POSSIBLE

Changing culture and the language used by staff

1. Clinical lead with protected time
2. Champions
3. Steering group
4. Engagement meetings
5. Stepwise implementation
6. Good visual aids

OACC Measures implementation at MCHWM



Phase and Karnofsky

1. Allow 6 months to embed
2. Use across all areas
3. Introduce language into all handovers, MDTs, clinical review etc
4. Encourage creativity of staff

DYING

STABLE

DETERIORATING

UNSTABLE

Care and support through terminal illness

Start of phase	End of phase
Stable: • Patient problems and symptoms are adequately controlled by established plan of care ***and*** • Further interventions to maintain symptom control and quality of life have been planned ***and*** • Family/carer situation is relatively stable and no new issues are apparent	**Stable:** • The needs of the patient and or family/carer increase, requiring changes to the existing plan of care
Unstable: An urgent change in the plan of care or emergency treatment is required because • Patient experiences a new problem that was not anticipated in the existing plan of care, ***and/or*** • Patient experiences a rapid increase in the severity of a current problem ***and/or*** • Family/ carers circumstances change suddenly impacting on patient care	**Unstable:** • The new care plan is in place, it has been reviewed and no further changes to the care plan are required. . This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. the patient is stable or deteriorating) ***and/or*** • Death is likely within days (i.e. patient is now terminal)
Deteriorating: The care plan is addressing anticipated needs but requires periodic review because • Patient's overall functional status is declining ***and*** • Patient experiences a gradual worsening of existing problem ***and/or*** • Patient experiences a new but anticipated problem ***and/or*** • Family/carers experience gradual worsening distress that impacts on the patient care	**Deteriorating:** Patient condition plateaus (i.e. patient is now stable) ***or*** • An urgent change in the care plan or emergency treatment ***and/or*** • Family/ carers experience a sudden change in their situation that impacts on patient care and urgent intervention is required (i.e. patient is now unstable) ***or*** • Death is likely within days (i.e. patient is now terminal)
Dying: Low complexity • **Death is likely within days** • Patient problems and symptoms are adequately controlled by established plan of care ***and*** • Further interventions to maintain symptom control and quality of life have been planned ***and*** • Family/carer situation is relatively stable and no new issues are apparent	**Dying: Low complexity** • Patient dies ***or*** • Patient condition changes and death is no longer likely within days (i.e. patient is now stable . or deteriorating)
Dying: High complexity • **Death is likely within days** An urgent change in the plan of care or emergency treatment is required because • Patient experiences a new problem that was not anticipated in the existing plan of care ***and/or*** • Patient experiences a rapid increase in the severity of a current problem ***and/or*** • Family/ carers circumstances change suddenly impacting on patient care	**Dying: High complexity** • Patient dies ***or*** • Patient condition changes and death is no longer likely within days (i.e. patient is now stable . or deteriorating)

hospice UK

KINGS College LONDON

Standardising a palliative care first assessment May 2015

This is a guide to the main components of a detailed palliative care assessment. It is based on Richardson A. Holistic Common Assessment of Supportive and Palliative Care Needs for People with Cancer: Report to the National Cancer Action Team. London: King's College London, 2007.

Disease update:

Summary of illness history, extent of disease, current management plan.

What phase of illness is the patient in? (Australian 'phase of illness' definitions):

Phase	This is the current phase if...	This phase ends when...
Stable	[illegible]	[illegible]
Unstable	[illegible]	[illegible]
Deteriorating	[illegible]	[illegible]
Dying	[illegible]	[illegible]
Deceased	[illegible]	Case is closed.

Patient's current functional status (Australia modified Karnofsky Performance Status):

AKPS Score	Description of Performance Status
100%	[illegible]
90%	[illegible]
80%	[illegible]
70%	[illegible]
60%	[illegible]
50%	[illegible]

Care and support through terminal illness

IPOS/Views on care

1. Allow at least 6 months to embed
2. Training for staff
3. Establish clear processes:
   - Who will have responsibility for ensuring patient completes these and who will enter onto the EPR
   - Frequency
   - How you will use them

Care and support through terminal illness

POS

Patient name……………………………………

DoB………………………………………………

NHS No…………………………………………

Date Completed………………………………

PROM A 1st Assessment IPU

Q1. What have been your main problems or concerns over the past 3 days?

1.

2.

3.

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0☐	1☐	2☐	3☐	4☐
Shortness of breath	0☐	1☐	2☐	3☐	4☐
Weakness or lack of energy	0☐	1☐	2☐	3☐	4☐
Nausea (feeling like you are going to be sick)	0☐	1☐	2☐	3☐	4☐
Vomiting (being sick)	0☐	1☐	2☐	3☐	4☐
Poor Appetite	0☐	1☐	2☐	3☐	4☐
Constipation	0☐	1☐	2☐	3☐	4☐
Sore or Dry Mouth	0☐	1☐	2☐	3☐	4☐
Drowsiness	0☐	1☐	2☐	3☐	4☐
Poor mobility	0☐	1☐	2☐	3☐	4☐
Please list any other symptoms not mentioned above, and tick one box to show how they have affected you					
1	0☐	1☐	2☐	3☐	4☐
2	0☐	1☐	2☐	3☐	4☐
3	0☐	1☐	2☐	3☐	4☐

Over the past 3 days

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about you illness or treatment?	0☐	1☐	2☐	3☐	4☐
Q4. Have any of your family or friends been anxious or worried about you?	0☐	1☐	2☐	3☐	4☐
Q5. Have you been feeling depressed?	0☐	1☐	2☐	3☐	4☐

PLEASE TURN OVER

Patient reported outcome measures

IPOS

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POS

Patient name……………………………………

DoB………………………………………………

NHS No…………………………………………

Date Completed………………………………

PROM A continued PROM A 1st Assessment IPU

	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0☐	1☐	2☐	3☐	4☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0☐	1☐	2☐	3☐	4☐
Q8. Have you had as much information as you wanted?	0☐	1☐	2☐	3☐	4☐
	Problems/ addressed/ No Problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed?(Such as financial or personal).	0☐	1☐	2☐	3☐	4☐
Q10. How did you complete this questionnaire?	On My Own ☐	With help from Staff ☐ Friend ☐ Relative ☐ Please print full name below		Staff member only ☐ Signature, Name (printed) & designation below	

Comments

Care and support through terminal illness

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Views on Care

1. How would you rate your overall quality of life in the 3 days before you came into the hospice?

(very poor) 1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	(Excellent) 7 ☐

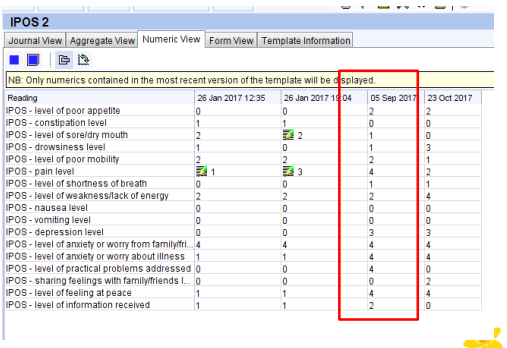
2. Over the past 3 days, thinking about your main problems and concerns would you say that:

Things have got much better	Things have got a little better	There has been No change	Things have got a little worse	Things have got much Worse	I Don't Know
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐

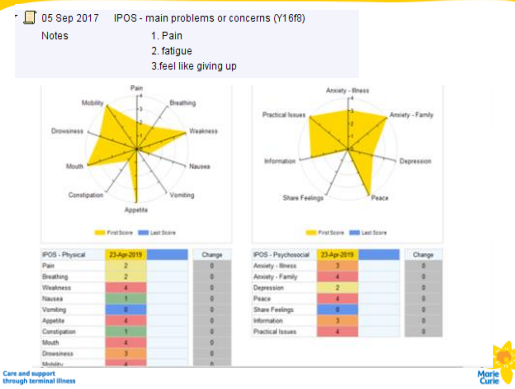
3. Thinking about how things are going for you today, how do you rate your overall Quality of Life today?

(very poor) 1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	(Excellent) 7 ☐

Views on Care/Comments:



Reading	26 Jan 2017 12:35	26 Jan 2017 13:04	05 Sep 2017	23 Oct 2017
IPOS - level of poor appetite	0	0	2	2
IPOS - constipation level	1	1	0	0
IPOS - level of sore/dry mouth	2	2	1	0
IPOS - drowsiness level	1	0	1	3
IPOS - level of poor mobility	2	2	2	1
IPOS - pain level	1	3	4	2
IPOS - level of shortness of breath	0	0	1	1
IPOS - level of weakness/lack of energy	2	2	2	4
IPOS - nausea level	0	0	0	0
IPOS - vomiting level	0	0	0	0
IPOS - depression level	0	0	3	3
IPOS - level of anxiety or worry from family/fri...	4	4	4	4
IPOS - level of anxiety or worry about illness	1	1	4	4
IPOS - level of practical problems addressed	0	0	4	0
IPOS - sharing feelings with family/friends i...	0	0	0	2
IPOS - level of feeling at peace	1	1	4	4
IPOS - level of information received	1	1	2	0



IPOS - Physical	23-Apr-2019	Change
Pain	2	0
Breathing	2	0
Weakness	4	0
Nausea	1	0
Vomiting	0	0
Appetite	4	0
Constipation	1	0
Mouth	4	0
Drowsiness	3	0
Mobility	4	0

IPOS - Psychosocial	23-Apr-2019	Change
Anxiety - Illness	3	0
Anxiety - Family	4	0
Depression	2	0
Peace	4	0
Share Feelings	0	0
Information	3	0
Practical Issues	4	0

IDEAL…..

Timing of OACC Outcome Measures

Follow the steps overleaf:

1. capture measures at first assessment by team
2. then monitor Phase of Illness
3. when Phase changes, repeat outcome measures
4. if Phase changes again, repeat outcome measures each time
5. try to capture outcome measures before discharge

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Reality

Community/OPAs

- On each contact
- Leaving them with Pt vs completing them with the patient

IPU

- On admission-easy
- Phase change
  - How does that trigger an IPOS/VOC review?
  - Who completes them?
- Once in deteriorating phase how often should we complete
- On discharge-easy
- Dying phase-Dr

CHALLENGES

1. Need to demonstrate that the results are being used for staff to engage with the process
2. Staff groups difficult to engage (Relates to no. 1)
3. Clear re Pt vs staff version
4. Up to date version vs burden on Pt and staff
5. Champions on the ground from different disciplines (AHPs)
6. Ongoing training programme
7. Constant energy and enthusiasm


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QUESTIONS?
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