Outcome Measures in Practice ECHO Network

WEEK 15: Thursday 28 October 2021
Network Recording Declaration

During this ECHO session discussions will be recorded so that people who cannot attend will be able to benefit at another time. Filming is regarded as ‘personal data’ under the General Data Protection Regulations (GDPR) under that law we need you to be aware that this Data will be stored with password protection on the internet.

This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.
Welcome

Julie Kinley
Research and Clinical Innovation
Project Lead

www.hospiceuk.org
# Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Presenter(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>15:30</td>
<td>Introductions</td>
<td>All</td>
</tr>
<tr>
<td>15:35</td>
<td>Triage, Complexity &amp; Case Load management – How can the OACC outcome measures help?</td>
<td>Prof Fliss Murtagh, Professor of Palliative Care at Hull York Medical School, Associate Director of the Wolfson Palliative Care Research Centre and an NIHR Senior Investigator.</td>
</tr>
<tr>
<td>16:05</td>
<td>Summary of presentation given on 23 September ECHO session and questions and discussion</td>
<td>Kerry Bareham, Nurse Consultant, St Barnabas Hospice</td>
</tr>
<tr>
<td>16:30</td>
<td>Issue presentation 1</td>
<td>Dr Joanne Droney, Consultant in Palliative Medicine The Royal Marsden and Royal Brompton Palliative Care Service The Royal Marsden NHS Foundation Trust</td>
</tr>
<tr>
<td>17:00</td>
<td>Close</td>
<td></td>
</tr>
</tbody>
</table>
Prof Fliss Murtagh
Professor of Palliative Care at Hull York Medical School, Associate Director of the Wolfson Palliative Care Research Centre and an NIHR Senior Investigator.
A HOLISTIC, INTEGRATED APPROACH TO END-OF-LIFE CARE IN LINCOLNSHIRE

Aims

Kerry Bareham
Nurse Consultant
Dip HE BA (Hons) MSc Queens Nurse

The Lincolnshire collaborative approach to palliative and end of life care
How we have used the language of Phase of Illness to do this
What we have learned
Lincolnshire has a challenging community with complex needs, deprivation and rurality – requiring access to multiple professionals.

**NHS**
The NHS 10 year plan (2019) provides a vision of fully integrated services focused on the community.

Research repeatedly identifies the negative impact that poor coordination and collaboration of health and social care has on patient outcomes.

**NHS England - Personalised Care Group**
Set priorities for PEOL Care – personalised care and shared decision making.

**Latest White Paper (ICS) DHSC 2021**
Sets to provide a legislative framework to enable the health and social care system to become integrated.

Palliative care is a key enabler to high quality care for people with complex needs.
This has enabled us to articulate what a specialist palliative care service looks like.
How specialist and generalist palliative care Services work together in Lincolnshire

<table>
<thead>
<tr>
<th>Specialist Palliative Care</th>
<th>Community Nursing Services</th>
<th>Primary Care</th>
<th>Social Prescribing and Wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red</td>
<td>Red</td>
<td>Red</td>
<td>Red</td>
</tr>
<tr>
<td>Amber</td>
<td>Amber</td>
<td>Red</td>
<td>Red</td>
</tr>
<tr>
<td>Green</td>
<td>Green</td>
<td>Amber</td>
<td>Red</td>
</tr>
<tr>
<td>Green</td>
<td>Green</td>
<td>Amber</td>
<td>Red</td>
</tr>
<tr>
<td>Green</td>
<td>Green</td>
<td>Amber</td>
<td>Green</td>
</tr>
</tbody>
</table>
Definitions: Specialist Palliative Care

**RED**
Unstable, rapidly deteriorating/ dying, in need of acute physical symptom management – without which will result in an unplanned admission imminently.

Initial Assessment and care planning initiated – SpMDT Review – Confirm Red Need – on going input according to case management need.

**AMBER**
At risk of deteriorating, in need of anticipatory care planning however not at risk imminent unplanned admission, known to other services who are having regular input. May benefit from shared plan of care with Community Nursing Team to be discussed at huddles

Initial Assessment and care planning initiated – SpMDT Review – Confirm Amber Need – Communication with other service: Open referral to be escalated back to team if and when need becomes RED

**Green**
Stable, no complex needs, at risk of deteriorating in the future, needs anticipatory care planning however not at risk of imminent unplanned admission

Initial Assessment and care planning initiated – SpMDT Review – Confirm Green Need – Communication with other individual and other service if known: Open referral to be escalated back to team if and when need becomes RED.
Using Phase of Illness to articulate which service best placed to case manage

<table>
<thead>
<tr>
<th>CARER FACTORS</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
<th>Phase of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal carer within the home and managing care. Care package not required</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>CN</td>
<td>SPC</td>
<td>CNS/SNP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal carer within the home. Established care package meeting needs</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>CN</td>
<td>SPC</td>
<td>CNS/SNP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives alone. Care needs being met</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>CN</td>
<td>SPC</td>
<td>CNS/SNP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal carer in the home. Current care package not meeting needs</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>PC</td>
<td>CN</td>
<td>SPC</td>
<td>CNS/SNP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer breakdown, stress/ill health. Care package in place</td>
<td>CN</td>
<td>CN</td>
<td>CN</td>
<td>CN</td>
<td>CN</td>
<td>CN</td>
<td>SPC</td>
<td>CNS/SNP</td>
<td>CNS/SNP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Casemanaged by Primary Care
Casemanaged by Community
Casemanaged by SCPCT

where does ASC fit? NTs? Any other services case-managing?
Summary

• There are significant demographic and workforce challenges in delivering high quality palliative care.

• The development of a conceptual framework describing the principles of specialist palliative care and how this integrates with generalist palliative care has been key in improving collaboration and reducing duplication.

• Palliative care is a key enabler in high quality care for people with complex needs.

• The shared language of Phase of Illness has enabled Specialist and Generalist Palliative Care Services to work together to:
  ❖ Recognise complex needs
  ❖ Develop a consistent approach to triage and response
  ❖ Develop shared plans of care
  ❖ Improve outcomes for people with palliative care needs
  ❖ Identify and respond to system learning needs through the use of Project ECHO
Complexity, Triage, and Case Load Management

How can the OACC outcome measures help in a Tertiary Referral Cancer Centre?

Dr Joanne Droney
Consultant Symptom Control and Palliative Care Team
Royal Marsden NHS Foundation Trust

28th November 2021
Challenge:

• How can we offer a high quality palliative care service for all patients who need it?

• Can Patient Centred Outcome measures help
  • Define complexity
  • Triage who should be seen, when and by whom
  • Manage Case Load
How can we offer a high quality palliative care service for all patients who need it?

Palliative care should be:

- Available to patients **early** in the course of their illness
- Integrated into standard oncology care **alongside** active cancer treatment

Projected increase in numbers of people with serious health-related suffering

Sleeman K et al, Lancet 2019

Number of people estimated to require palliative care by age 2014-2040

Etkind S et al, BMC Medicine 2017
Palliative Care at the Royal Marsden

Hospital Support

“Triggers” Outpatient Service

Hospital to Home

Proactive

From diagnosis

Alongside anti-cancer therapy

Individual patient’s needs

Annual activity

1782 Patients

2634 Episodes of care

11135 Consultations

New Patients

38-39% Triggers Outpatient Service

Hospital Support Team and Hospital To Home

100% 90% 80% 70% 60% 50% 40% 30% 20% 10% 0%
Royal Marsden Inpatient Palliative Care Outcome and Activity Data

Admitted to RM

Referred to palliative care team

Discharge or death

Hospital admission

Episode of care / Spell of care

Consultations and Contacts

Initial

IPOS Phase Performance status

Follow-up

IPOS Phase Performance status
Inpatient complexity, triage, effectiveness

**Inpatient Phase of Illness**

<table>
<thead>
<tr>
<th>Status</th>
<th>Start of Episode</th>
<th>End of Episode</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>40%</td>
<td>50%</td>
</tr>
<tr>
<td>Unstable</td>
<td>30%</td>
<td>35%</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>10%</td>
<td>15%</td>
</tr>
<tr>
<td>Dying</td>
<td>5%</td>
<td>10%</td>
</tr>
<tr>
<td>Missing</td>
<td>5%</td>
<td>10%</td>
</tr>
</tbody>
</table>

**AKPS Inpatients start of episode**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;40</td>
<td>35%</td>
</tr>
<tr>
<td>50-70</td>
<td>46%</td>
</tr>
<tr>
<td>&gt;70</td>
<td>4%</td>
</tr>
<tr>
<td>Missing</td>
<td>15%</td>
</tr>
</tbody>
</table>
Inpatient complexity, triage, effectiveness

**Inpatient Phase of Illness**

- **Start of Episode**
  - Stable: 40%
  - Unstable: 50%
  - Deteriorating: 10%
  - Dying: 5%
  - Missing: 5%

- **End of Episode**
  - Stable: 30%
  - Unstable: 35%
  - Deteriorating: 15%
  - Dying: 10%
  - Missing: 5%

**AKPS Inpatients start of episode**

- **<40**
  - 35%

- **50-70**
  - 46%

- **>70**
  - 4%

- **Missing**
  - 15%

**Proportion of patients with moderate, severe or overwhelming score for each palliative care need on initial assessment**

- Pain
- Poor appetite
- Weakness
- Patient anxiety
- Family anxiety
- Information needs

- **Baseline assessment**
- **Persistent at end of episode**
- **Resolved at end of episode**

- Pain: 63%
- Poor appetite: 35%
- Weakness: 44%
- Patient anxiety: 65%
- Family anxiety: -60%
- Information needs: -60%
Models of Early Outpatient Palliative Care at RMH

Proactive Palliative Care for patients with potentially incurable disease

- Renal cancer
- Gynaecological cancer
- Haematological cancer

Proactive Palliative Care for patients from diagnosis of cancer: “Triggers” service

- Lung cancer
- Upper GI
- Sarcoma
Triggers Tool to proactively identify cancer outpatients for Palliative Care review

Palliative care team involvement alongside active anti-cancer therapy

Proactive Palliative Care for patients from diagnosis of cancer

Underpins a new Integrated Palliative Care and Oncology Service

Specialist Palliative Care Referral Triggers Tool

Patient is “Trigger positive” if they have any one of the following:
- Metastatic cancer progressing after 1st line of treatment
- Performance status ECOG 2 and deteriorating
- Acute oncology or unplanned admission
- Severe or overwhelming symptoms
- Anorexia, hypercalcemia, or any effusion
- Moderate or severe psychological or existential distress
- Complex social issues

RM Partners. London Cancer Alliance Palliative Care and End of Life Care Pathway Group. The Transition to Palliative Care.
http://www.londoncanceralliance.nhs.uk

Early Palliative Care Service Royal Marsden NHS Foundation Trust
October 2021
“Triggers” Outpatient Palliative Care Service: A Complex Intervention

- Integrated working
- Patient engagement and education
- Oncology staff training, education and engagement
- Novel work flow for palliative care team
- Patient Reported Outcome Measures
- Advance Care Planning

Trigger Tool
“Triggers”: A New Integrated Palliative Care Service

Initial Assessment
All new outpatient cancer patients

Trigger tool
(oncology team)

Follow-up next clinic

Trigger positive

Triggers Team Nurse Assessment

• Assessment of palliative care needs using IPOS
• Provide information about palliative care in hospital and community
• Provide information about Advance Care Planning

Intervention to address palliative care needs

Referral to community team or other services as needs require

Advance Care Planning

Monthly follow up to assess needs and outcomes
Early Palliative Care “Triggers” service for lung outpatients

- 89% (921/1037) eligible new lung patients assessed
- 55% new patients “Trigger” positive
- 70% WHO Performance status 0-1
Proportion of patients with palliative care needs
Outpatient complexity
Lung “Triggers” service: Evidence of acceptability, need and effectiveness

- Patients are reviewed by Palliative Care earlier

- Improved quality of life

- Severe or overwhelming physical needs at Baseline: ↓61%, ↓71%, ↓72%
Lung “Triggers” service: Evidence of acceptability, need and effectiveness

Patients are reviewed by Palliative Care earlier

Improved quality of life

I’m not sure what I would have done without the support of the palliative care team and their help with managing the side effects from my condition. The Royal Marsden is a wonderful place, you don’t realise the amazing work they do until you’re involved in it.

Edwin Boyce, 76
Lung cancer patient, benefiting from an early needs assessment via the Triggers tool
Early Palliative Care at the Royal Marsden

Service development
- Expansion to other tumour groups
- Enhanced Integration: MDTs, decision making, ACP
- Integration with other initiatives: Prehabilitation, Living With and Beyond Cancer
- Expansion outside RM

Research / service evaluation
- Validate approach
- Patient and staff experience
- Transferability & effectiveness of service
- Economic evaluation
- Tumour specifics

Support from:
RM Trust Transformation Teams
RM Partners
Patient and Public Involvement
RM Cancer Charity

The ROYAL MARSDEN
NHS Foundation Trust
ECHO Session Evaluation

Help to shape the sessions by entering your key takeaway from this session and any other feedback you have.

https://www.surveymonkey.co.uk/r/28-Oct-2021-OMiP