Outcome Measures in Practice ECHO Network

Session 16: Triage, Complexity & Case Load Management – How can the OACC Outcome Measures help?, Spirituality & Curriculum Setting
19th January 2022
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 Data Protection Act 2018 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.
### Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Presenters</th>
</tr>
</thead>
<tbody>
<tr>
<td>15:30</td>
<td>Introductions</td>
<td><strong>Julie Kinley</strong>, Research and Clinical Innovation Project Lead, Hospice UK</td>
</tr>
<tr>
<td>15:35</td>
<td>Integrating Outcome Measures into Standardised Assessment</td>
<td><strong>Helen Brewerton</strong>, Joint Head of Community Services, Royal Trinity Hospice</td>
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<tr>
<td>15:45</td>
<td>Questions and Group Discussion</td>
<td>All</td>
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<tr>
<td>15:55</td>
<td>Spirituality - How well are we assessing it? How can IPOS data be helpful?</td>
<td><strong>Dr Sarah Wells, Dr Anna Perry &amp; Nick Partridge</strong>, Marie Curie Hospice, West Midlands</td>
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<tr>
<td>16:05</td>
<td>Questions and Group Discussion</td>
<td>All</td>
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<tr>
<td>16:15</td>
<td>2022 Curriculum Setting</td>
<td><strong>Julie Kinley</strong>, Research and Clinical Innovation Project Lead, Hospice UK</td>
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<td>17:00</td>
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Integrating Outcome Measures into Standardised Assessment

Helen Brewerton
Joint Head of Community Services
Royal Trinity Hospice
Outcome Measures in Practice – Issue Presentation

Helen Brewerton, Joint Head of Community Services
19th January 2022
Key Issue - Integrating Outcome Measures into Standardised Assessment
Background to the Issue
Trinity introduced the IPOS alongside other OACC measures in 2014 but it wasn’t integrated into the standardised assessment proforma.

This I believe has led to:

➤ Inconsistent completion of IPOS
➤ Assessment led by clinician’s perception of problems and severity, not patients’
➤ Staff confusion about how to include IPOS into their core assessment and not being able to see the value of it (tick box exercise)
➤ Staff asking the IPOS questions at the end of the assessment leading to duplication of questions and effort for the patient.
➤ Staff ‘giving up’ on IPOS and high percentage of non-completion
➤ Lack of useful data for the clinicians on impact of interventions at an individual patient level
➤ Lack of useful data on impact or caseload complexity at a service level
What have we done to address this?

- All patients referred for community support have a first contact telephone assessment and we have included the 5Q IPOS as a way to identify needs, severity of needs, and urgency for full CNS assessment.

PRE-visit patients main concerns or goals

Please rank problems and concerns by priority high to low (1, 2, 3).

What are your main problems or concerns at the moment?

Below is a list of symptoms, which you may or may not have experienced. For each please select how it has affected you:

- Pain:
  - Not at all
  - Slightly
  - Moderately
  - Severe
  - Overwhelmingly
  - Cannot assess (e.g., unconscious)
  - Not Assessed

- Shortness of breath:
  - Not at all
  - Slightly
  - Moderately
  - Severe
  - Overwhelmingly
  - Cannot assess (e.g., unconscious)
  - Not Assessed

- Anxious or worried:
  - No - not at all
  - Occasionally
  - Sometimes
  - Most of the time
  - Yes - always
  - Cannot assess (e.g., unconscious)
  - Not Assessed

- Feel at peace:
  - Always
  - Most of the time
  - Sometimes
  - Occasionally
  - Not at all
  - Cannot assess (e.g., unconscious)
  - Not Assessed
I developed a common assessment proforma for community clinical staff - to act as an aide memoire to ensure consistency of assessment, and to record assessment at the time. I have updated to include the IPOS Qs where relevant.

<table>
<thead>
<tr>
<th>Physical Wellbeing</th>
<th>Social and Occupational Wellbeing</th>
<th>Spiritual Wellbeing</th>
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</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Household, family and support network detail</td>
<td>Sources of hope/strength/comfort</td>
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<td></td>
<td>Symptoms of breath</td>
<td>Relationship or intimacy concerns</td>
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<td></td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<tr>
<td></td>
<td>Shortness of breath</td>
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<tr>
<td>Upper GI</td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<tr>
<td>Poor appetite</td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<td>Nausea</td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<td>Vomiting</td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<td>Bowels</td>
<td>Cardiovascular e.g. angina, pain, ECG/PIM</td>
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<td>Constipation</td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<td>Urinary</td>
<td>Skin/cordial wounds</td>
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<td>Sleep</td>
<td>Weakness or lack of energy</td>
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<td></td>
<td>Not at all/ slightly/severely overwhelmingly</td>
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<tr>
<td>Poor Mobility</td>
<td>Functional status (Complete – Karnofsky below FAKS)</td>
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<td>Trouble walking/bodily</td>
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<td>Drowsiness (sleepless)</td>
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<td>Neurology (other including Cognition)</td>
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<td>Have you felt at peace?</td>
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<td>Always/Most of the time/ sometimes/ occasionally/ not at all</td>
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<td>Is there something the spiritual care team could support you with?</td>
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<td>Have you been able to share how you are feeling with your family and friends as much as you wanted?</td>
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<td>Always/Most of the time/ sometimes/ occasionally/ not at all</td>
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<td>Housing ownership or home environment concerns which impact on symptoms management or care arrangements</td>
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<td>Details of children/young adults in family</td>
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<td>Any observed or disclosed safeguarding concerns</td>
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<td>Social and recreational</td>
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<td>Financial concerns</td>
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<td></td>
<td>Equipment needs</td>
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<td>Have you been feeling anxious or worried about your illness or treatment?</td>
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<td>Always/Most of the time/ sometimes/ occasionally/ not at all</td>
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<td>Resources and strengths and how do you use you coping?</td>
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<td></td>
<td>Have you been feeling depressed?</td>
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<td>Always/Most of the time/ sometimes/ occasionally/ not at all</td>
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<td></td>
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<td>Previous or current mental health problems?</td>
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</table>
Borrowing from St Barnabas Hospice

After agonising for many months about how to use the OACC suite of measures to guide response to referral and caseload management, I gained inspiration from hearing Kerry Bareham speak at OMiP last year!

Trinity’s service is different to St Barnabas, but using a RAG rating to help identify urgency and ensure responsiveness is such a simple way to manage with such a large cohort of patients. With medical and AHP colleagues, we have tweaked the St Barnabas RAG rating system and we are using it for the following processes:

• As part of triage when initially referred
• To identify which patients should be discussed at IDT meetings
• To identify which patients to focus on within a large caseload if staff off sick (COVID!)
• To identify which patients can be reviewed by band 3 and band 5 staff
• To determine which patients might be suitable for discharge from SPC services
Trinity’s version of the RAG rating

RAG rating for triage, CNS allocation, and caseload management

**Red**
- Phase of illness unstable or dying with other factors listed below.
- Rapid change in Karnofsky status (over days)
- Prognosis of hours or days
- Carer breakdown, stress/ill health
- No care package in place or current care package not meeting needs
- Patient has delirium
- Uncontrolled symptoms not responding to current plan OR Uncontrolled symptoms. No plan or medication in place
- Not known to District Nursing services/other relevant primary care teams and or District Nursing Services/primary care teams unable to manage without specialist palliative care support.

**Amber**
- Phase of illness deteriorating or dying with no patient or family concerns.
- Gradual but steady decline in Karnofsky status (over weeks)
- Prognosis of weeks
- Current care package needs regular review to ensure it is meeting needs.
- Patient has a history of delirium
- Uncontrolled symptoms but plan in place
- Not known to community nursing services or not receiving regular monitoring from them or other primary care services.

**Green**
- Phase of illness stable
- Slow decline in Karnofsky status (over months)
- Prognosis of months
- Symptoms controlled
- Informal carer within the home and managing care OR has established care package which is meeting needs.
- Regular monitoring via community nursing services or other primary care services.
What next?

» Fully adopt all OACC measures and the RAG rating for processes highlighted earlier

» Ensure the OACC measures ‘language’ and the RAG rating becomes standardised part of patient management i.e. presentation at IDT meetings, patient handover between clinical staff, caseload reviews and decision to admit to Hospice or discharge from caseload.

» Incorporate IPOS Dem Qs into the Common Assessment Proforma, as we see a lot of patients with Dementia and the Qs are relevant for other patients

» Use the Common Assessment Proforma and RAG rating as the building blocks to design the fields when we transition to a new electronic patient record system later this year (Crosscare to EMIS)

Thank you for listening 😊
Spirituality - How well are we assessing it? How can IPOS data be helpful?

Dr Sarah Wells, Consultant in Palliative Care and Medical Director
Dr Anna Perry, Specialty Doctor
Nick Partridge, Volunteer Chaplain

Marie Curie Hospice, West Midlands

www.hospiceuk.org
Spirituality-How well are we assessing it? How can IPOS data be helpful?

Outcome measures ECHO
19th January 2022
Dr Anna Perry-Specialty Doctor
Nick Partridge-Volunteer Chaplain
Dr Sarah Wells-Medical Director and Palliative Medicine Consultant
Marie Curie Hospice West Midlands
Agenda

1. Spirituality MA overview
2. Spirituality IPOS data
3. Observations
4. Next steps
How is the concept of ‘spiritual need’ understood and assessed at Marie Curie’s nine UK hospices.

by Nick partridge
The understanding of spirituality

Over recent decades religious care has largely been replaced by spiritual care in the UK healthcare sector.

Understanding of the terms ‘spirituality’ and ‘spiritual care’ is not always good amongst patients or caring staff. In a recent research project, Less than 50% of Marie Curie caring staff disagreed with the following statement: ‘Spiritual care is such a nebulous concept that it's hard to understand what it's all about.’
The marginalisation of spiritual care

If staff don’t understand the importance of spiritual care, it is possible that spiritual care will become marginalised, suffer from additional budgetary pressure or even be reduced to voluntary function.

Employing a spiritual care lead at each hospice should help to improve the provision and maintain the profile of spiritual care.
Understanding ‘spirituality’

Spirituality is about **questions of meaning, purpose and connection.** Such questions can become particularly important in a palliative context.

**A simple definition may also be helpful:**

*Spirituality can be defined as the element of human existence that seeks for meaning and purpose in life. This search for meaning and purpose may or may not relate to a belief in God or some form of higher power. As such spirituality often focusses on questions about how an individual connects to God, the Divine, nature or even simply to his / her own place or role in the universe.*

Nick Partridge 2020

**Additional training should help to improve understanding**
Assessing spiritual needs

If spiritual needs are not assessed and addressed, some patients will pass through the hospice system without receiving any care for their greatest source of pain and distress. Spiritual assessment is particularly important for patients with high IPOS scores indicating a lack of peace.

Assessment Tools

An academic study published in 2015 found that the ‘HOPE’ spiritual assessment tool was the most effective spiritual assessment tool in a palliative context.
HOPE – spiritual assessment tool

The Initial ‘H’ Questions: Sources of hope, meaning, comfort, strength, peace, love and connection

• We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support?
• What do you hold on to during difficult times?
• What sustains you and keeps you going?

The ‘triage’ question

For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; would you say this is true for you?
The recommendations

• Additional training

• Employing a spiritual care lead at each hospice

• Making the ‘HOPE’ assessment tool available within electronic records
Use of IPOS at Marie Curie Hospice, West Midlands

- 4 years experience of using IPOS
- 3,482 IPOSs on first assessment carried out
- Analytics introduced capturing data over the 4 year period
- Filters to enable interrogation of data
# Data filters

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<th>Filter</th>
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<td>Year</td>
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<td>Organisation</td>
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<td>Service Offered</td>
<td>Adult Bereavement, Bereavement</td>
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<td>GP_Practice</td>
<td>V81999, Acocks Green Medical C</td>
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<td>Sex</td>
<td>F, M, U</td>
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<td>IPOS Completed By</td>
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<td>Usual Residence</td>
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<td>Has Mental Illness</td>
<td>No, Yes</td>
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<td>Chart Scale</td>
<td>Auto</td>
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<tr>
<td>Month</td>
<td>April, May, June, July, August, Sep</td>
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<tr>
<td>Care Setting</td>
<td>Community, Inpatient, Outpatient</td>
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<tr>
<td>Postcode</td>
<td>00NK (00NK), Acocks Green (B2)</td>
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<tr>
<td>Diagnosis</td>
<td>[X] Dementia in Alzheimer's disease</td>
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<tr>
<td>Age Group</td>
<td>15 to 19, 20 to 24, 25 to 29,</td>
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<td>Religion</td>
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<td>Referral Source</td>
<td>Allied Health Professional, Ambulance</td>
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<td>Discharge Reason</td>
<td>Death, Discharge, Unset</td>
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<tr>
<td>Lives Alone</td>
<td>No, Yes</td>
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<tr>
<td>Has Learning Disability</td>
<td>No, Yes</td>
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</tbody>
</table>
Bar chart showing IPOS scores 2-4 at 1st assessment

IPOS First Assessment

Moderate, severe or overwhelming symptoms or problems at first assessment (score > 1)

- **Month(s):** All Months
- **Number of Spells:** 8,067
- **Spells with first IPOS:** 3,620
- **Care Setting:** Community, inpatient, outpatient

### Physical

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Occurrence</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Constipation</td>
<td>1107</td>
<td>29%</td>
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<tr>
<td>IPOS - drawsiness level</td>
<td>1351</td>
<td>36%</td>
</tr>
<tr>
<td>IPOS - level of poor appetite</td>
<td>2073</td>
<td>54%</td>
</tr>
<tr>
<td>IPOS - level of poor mobility</td>
<td>2795</td>
<td>71%</td>
</tr>
<tr>
<td>IPOS - level of weakness/lack of energy</td>
<td>3024</td>
<td>79%</td>
</tr>
<tr>
<td>Nausea</td>
<td>638</td>
<td>17%</td>
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<tr>
<td>Pain</td>
<td>1904</td>
<td>50%</td>
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### Psychosocial

<table>
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<tr>
<th>Symptom</th>
<th>Occurrence</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Anxiety from family or friends</td>
<td>2523</td>
<td>66%</td>
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<tr>
<td>Anxiety or worry about illness</td>
<td>1703</td>
<td>45%</td>
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<tr>
<td>Depression</td>
<td>923</td>
<td>24%</td>
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<tr>
<td>Feeling at peace</td>
<td>1181</td>
<td>31%</td>
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<tr>
<td>Information received</td>
<td>471</td>
<td>12%</td>
</tr>
<tr>
<td>IPOS - level of practical problems addressed</td>
<td>491</td>
<td>13%</td>
</tr>
<tr>
<td>IPOS - sharing feelings with family/friends level</td>
<td>834</td>
<td>22%</td>
</tr>
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</table>

Click data series in chart to drill to patient details
Interrogation of the “At peace” question data

Total patients with ‘at peace’ scores 2-4 at first IPOS recorded= 1087/3491 = 31%

- Gender
- Age
- Ethnicity
- Religion
- Diagnosis
- Lives alone
No Gender difference noted
Younger people were more likely to report a lack of peace and this reduces proportionally with advancing years.
Residence status

- Numbers were too low.
- Does not correlate with clinical experience
Ethnicity

Ethnicity

- White (incl British / Irish): 29%
- Asian (incl Indian, Pakistani, Bangladeshi, other Asian): 15%
- Black (incl African, Caribbean, other black): 18%
- Mixed ethnicity: 17%

Numbers were too low.
Predominantly White British patient cohort.
Religion

- Numbers were too low to draw conclusions
- Having no religious affiliation is associated with higher levels of lack of peace
Diagnosis

- 31% of patients with 'At Peace' scores 2-4 on 1st IPOS
- 29% of non-cancer patients

Thoughts?
Non-Cancer diagnoses

- Neurological conditions were associated with a significantly higher level of lack of peace.
Cancer diagnoses

- GI / Liver: 25%
- Lung: 27%
- Haematological: 32%
- Breast: 34%
- Brain: 25%
Reason for admission

- Terminal Care: 37%
- Symptom Control: 38%
- Respite: 24%

• Lower levels of lack of peace for respite patients—as expected
Observations-General

• Many domains had such small numbers that unlikely to be significant
• Coding accuracy essential
• Poor coding for:
  • Lives alone
  • Mental illness
  • Learning disability
Case reviews

10 sets of patient notes reviewed at random from 2020-21 with “At Peace “score of 4
Notes reviewed for the following:
  • Age
  • Diagnosis
  • Setting
  • Chronology of IPOS at peace scores
  • Concurrent IPOS scores for:
    • Patient anxiety
    • Family anxiety
    • Pain scores
  • Documentation of religion and spiritual support given
  • Documentation of psychological support
Case review findings

Broad analysis of themes:

- High lack of peace scores correlated strongly with high scores for both patient and family anxiety.
- There was not a clear correlation with high pain scores.
- All had psychological assessment and often multiple entries.
- Religious affiliations were poorly recorded, most had no entry at all.
- If no entry or stated as 'not religious' then there was typically no entry at all in the spirituality template.
- Only those with a recorded religion had spirituality exploration or support.
Observations

- Coding within S1 is poor in certain areas
- Staff do not feel confident in discussing spirituality
- Staff do not document in any detail around spirituality
- There is no clear pathway for escalation if high “At peace” scores are noted
- We appear to be unable to see spirituality care as separate from purely religious care
Next steps

• Review and refine coding in SystmOne
• Appoint spiritual lead
• Training for staff in spiritual assessment
• Select spiritual assessment tool
• Develop a spiritual care pathway
Questions?

Contact: sarah.wells@mariecurie.org.uk
### 2020 - 2021 Curriculum:

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
</tr>
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<tbody>
<tr>
<td>October</td>
<td>How to use data – patients, team &amp; organisational perspectives</td>
</tr>
<tr>
<td>November</td>
<td>Data extraction – SystmOne &amp; EMIS</td>
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<tr>
<td>February</td>
<td>How to use data – hospitals &amp; day services</td>
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<tr>
<td>March</td>
<td>How to use data – hospice at home services</td>
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<td>April</td>
<td>Rehabilitation &amp; goal attainment scaling [GAS-Light]</td>
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<td>June</td>
<td>Psychological symptoms closer to death</td>
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<td>September</td>
<td>Audits – unusual findings</td>
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<tr>
<td>October</td>
<td>Triage, complexity &amp; caseload management – how can the OACC outcome measures help?</td>
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# 2022 Curriculum:
(Unconfirmed)

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Issue Presenter 1</th>
<th>Issue Presenter 2</th>
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<tbody>
<tr>
<td>19th January</td>
<td>Triage, Complexity &amp; Case Load Management – OACC Outcome Measures, Spirituality &amp; Curriculum Setting</td>
<td>Helen Brewerton</td>
<td>Dr. Sarah Wells, Dr. Anna Perry, Nick Partridge</td>
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<tr>
<td>23rd February</td>
<td>Using Outcome Measures for Benchmarks</td>
<td>Fliss Murtagh</td>
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<td>23rd March</td>
<td>The Role of disease specific IPOS</td>
<td>Query Trinity Dementia Team</td>
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<tr>
<td>27th April</td>
<td>Using OACC measures to inform service design</td>
<td>Kerry Harrison - OJ</td>
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<td>25th May</td>
<td>Looking at family anxiety questions &amp; Career Support</td>
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<tr>
<td>22nd June</td>
<td>Other examples of how data has informed service development</td>
<td>David Waters</td>
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<td>21st September</td>
<td>Use of Data in the currency work the NHS are undertaking and how this might affect funding</td>
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<td>26th October</td>
<td>Implementation plans amongst community teams – checks and balances</td>
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<td>23rd November</td>
<td>Completing the deceased IPOS</td>
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Next Session:

Date: Wednesday 23rd February 2022
Time: 15:30 – 17:00

Topic: TBC
Before you go…

Let us know your feedback via this survey:

https://www.surveymonkey.co.uk/r/OMiPSurvey
Before you go…

In collaboration with Hull York Medical School two future opportunities for you to be aware of:

• 8th June – Webinar on ‘How can Outcome Measures Influence Policy?’ [9.30am – 12.30pm]
• 14th June – our third Implementing Evidence into Practice Webinar ‘Prevention, recognition and management of delirium: what works and how to put it into practice’ [11am-1pm]

Further details will be included in the Hospice UK Bi-Monthly Research & Evidence into Practice Bulletin.

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