TayPEOLC MCN Network & Engagement Event
31st August 2018
Discussion Session Report

1.0 Introduction

The TayPEOLC MCN held its first Network and Engagement Event on 31st August 2018, in the Dalhousie Building, University of Dundee. Over 120 colleagues from across Tayside working in the primary and secondary health care settings, including staff from specialist palliative care services, joined with others working in care homes, social care, the voluntary sector, and from higher education. There were also members of the public in attendance from NHS Tayside Public Partners who were also able to participate in an interesting and informative afternoon of talks and workshop sessions.

The breadth of interest in the event clearly demonstrated the intent of the Network to be collaborative and inclusive, enabling people to work together across traditional boundaries to support the planning and delivery of consistent, equitable, high quality services to meet the needs of patients and their families.

At the beginning of the plenary session delegates were asked the question ‘What Does Palliative Care Mean To You?’ and using an online interactive tool (Mentimeter) their feedback was captured producing the Wordle below.

Delegates then listened to presentations which described the progress of the MCN since its launch in October 2017. They also took the opportunity at the event to network with colleagues from other care sectors to share ideas, hear about new initiatives underway and make valuable connections.

The MCN team was keen to take the opportunity to seek the views of stakeholders at the event regarding palliative and end of life care. This was achieved through facilitated group discussions where they were asked to consider two questions:

- ‘What do you feel you, your community or organisation could do to improve palliative and end of life care in the future’
- ‘What do you think the priorities should be for the MCN?

The discussions were wide ranging and feedback from each of the groups has been collated. The main themes arising from these discussions are outlined below and key priorities for the MCN can be seen in Appendix 1 & 2, which were again captured using Mentimeter.

2.0 Key Themes

2.1 Communication and Person-Centred Care

The most common theme arising from the discussions was around communication. Thinking about how we speak to people, the language we use and the importance of establishing early and consistent communication links. Communication between care providers was een as essential for continuity of care. Also taking a person-centred approach in supporting and caring for patients and their families. Providing help to navigate the system, to understand what services are available and how to access them was highlighted.

- “Need to identify the patient’s wishes and needs of the family”
- “As a service user trying to understand the structure of the service/how things work- confusing”
- “Take away uncertainty and fear for family, carer and patient”
- “Signposting to what is available locally and not just palliative care services”
- “Communication...joined up care....between hospital and community”

Having ‘open and honest discussions’ with patients and their families were reflected in delegates comments.

- “Enable an active/effective listening platform”
- “Providing information about the choices available”
- “Managing expectations of patients and wider family members”
- “Patients preferred place of care can’t always be met”
- “...a change in culture, especially in respect of the perception of ‘cure’ and ‘treatment’”
- “Make decisions to treat conservatively rather than try to fix things. “Have the conversation”

It was suggested that there was a wider conversation to be had with the public regarding palliative care, death and dying.

- “Avoidance in discussing death”
- “Talking about death in schools”
- Need to improve “the public and workplace understanding of palliative care”

2.2 Information

Points were made relating to ease of access to information from the patients perspective, data sharing between healthcare professionals across different care sectors and calls for a single IT system:

- “Reaching people with pertinent information”
- “Ensuring appropriate cascading of information ie. so that the public understands”
- ”Consider those not online with no access to technology for information”
- “Transition to everybody using technology – not here yet”
- “Digital technology” – connecting people up - “Once for Scotland ‘App’ for patients with Directory”
- “Use of new technologies in engaging people in their treatment decisions”
- “Need document sharing wherever the patient is for personalised care”
- ”KIS information real time sharing”
- “Focus on improving community/sharing information in a timely fashion”
- “Different disciplines use different systems”
- “Single IT system across the IJB/MDT”

2.3 Education

Discussions touched on the importance of education and training not only for health and social care professionals but also for carers to enable them to care for their loved ones at home.

- “Education for all”
- “Up skilling the workforce to co-ordinate and deliver PEOLC” as it is uncertain “ what future healthcare provision/models will be
- Issue of “equality especially for the rural areas”
- Education and training across all the Health & Social Care Partnerships
- “Carers at home – support/education”

2.4 User Voice

It was recognised that service users/patients and carers need to have their views heard.

- “Patient user voice is central”
- “How we hear patient voice within service - design public involvement in forums”
- “Involvement of patient/carer (volunteers) into the development of policies/frameworks.
- “Ensuring ‘the lived experience’ is heard”
- “Satellite MCN events”

2.5 Anticipatory Care Planning

The importance of anticipatory care planning was noted by many groups but this required robust implementation and some ideas for improvements were made.

- “Communication from secondary care to care home to primary care needs improved”
- This is about a “Conversation not just documents”
- There needs to be “Clear documentation of conversation in records”.
- Conversations should be “...individual and the timing of this is essential.”
- “Alleviates fear”
- “Power of Attorney should be easier process”
- “Care home led ACP’s”
- “Allowing individuals to make their own choices re: EOLC – ensuring patients are aware of their ‘rights’”

2.6 Equality

Issues around equality focused on hard to reach groups, where people live as well as access to information and care.

- “Hard to reach people – deliberately hard to reach”
- “Geographical deprivation”
- ”Reducing inequality in care delivery between rural and urban areas”
- “Information services being shared”
- “Equity of access/opportunity”
- “Consistency and good care for everyone”
- “Access to specialist palliative services”

2.7 Referral Pathways

Discussions also noted the importance of appropriate and timely referrals and having effective pathways in place for all patients including those with cancer and non-malignant disease.

- “Appropriate referrals to specialist palliative services”
- “How do we ensure delivery to all diagnoses – especially non-malignant disease”
- “Referral pathways/what’s available and where – medical, spiritual, social, voluntary etc.”
- “Timely referral – to ensure we arrive at right time”
- “Pathways of care – develop and share”

2.8 Care for the Dying at Home (Including Out of Hours)

Various factors were identified which would facilitate this such as having access to the necessary resources eg. support, advice and medication especially out of hours.

- “Out of Hours – risky time”

- "Confidence/decision making, emotional for families"
- "Community nursing less experience"
- "Advice bleep held by ANP – community nurses, GP"
- "Joint visiting, support colleagues"
- "Access to "just in case" medicines is not working to full potential"
- "Lack of social care resources"
- "Unmet needs"
- "Specialist palliative care end of life team as outreach"

2.9 Hospital

There were some feedback relating to hospital based PEOLC. Issues were raised around the need for more personalised care and patient documentation.

- "Provide more personalised care - look to how care homes do it"
- "Admissions to hospital from care provider - extensive details given however the hospital does not read"
- "Hospital philosophy is reactive. Lots of unnecessary tick box documentation which is not helping patient centred care"

2.10 Workforce

Comments were also made in respect of frontline staff who deliver care and the need for them to be supported and feel valued in the work they do especially staff working in care homes.

- "Education and emotional support for social care/ care home staff"
- "Investment in front-line staff"
- "Social care workers being supported and fairly paid"
- "Ethos of looking after staff to train to retain – good workforce"
- "Take care of staff and they will look after the people well"
- "Value staff, provide career progression within care homes"
- "Training – 'compassion' – looking after yourself"

2.11 Transitions

Enabling transitions to palliative and end of life care was noted in some of the discussions.

- "Children and young people (also key age group 16-25), transitions complexity"
- "Transitional care to adult from paediatrics"
- "Achieving a more seamless transition from oncology to palliative care"

2.12 Integration and Coordination of Care

Discussions identified the key role integration and coordination can play in the provision of PEOLC.

- Integrated teams around General Practice
- Geographical alignment as an enabler of MDT working and personalised care.

- Specialists eg. Macmillan nurses/consultants
- No continuity of care anymore. Continuity and coordination of care should be provided by a key person who oversees the patients journey

3.0 Next Steps

This report and the themes arising from the discussion sessions will be discussed with the TayPEOLC MCN Steering Group on 1st November 2018. The aim will be to agree which key areas the MCN will focus on for the next 3-5 years. This will inform the MCN Workplan and direct the work of the subgroups.

Appendix 1: PRIORITIES FOR TAYPEOLC MCN (MENTIMETER)

1. **Consistency and good care** for everyone
2. Easier access to **bereavement support**
3. Appropriate **referrals/transitions** in to palliative

1. **Communication**
2. **Spiritual and holistic well being** for carers and professionals
3. **Equity** of service

1. **Keep doing what you are already doing**!!
2. **Let subgroups flourish and disseminate**
3. Ensure **patient and carer voice** throughout.
4. **Co-production** will be effective

1. **Communication** in all formats to be clear and accessible
2. **MCN to have influence nationally and locally** re. importance of ACP and issues relating to costs of POA
3. **Education** for all

1. **Information**
2. **Sharing**
3. **Engagement**
4. **Focus**

1. **Integration** at community level that links health and social care at all levels
2. **Identifying what we don't know about health and social care** perspectives and processes
3. **Building a directory** of who's who, how can we do this?

1. **Education** across all disciplines
2. **Equity** across all diagnoses
3. **Resource and information** management

1. Warm **collaboration** with and within IJBs
2. **Aligning local developments with national digital developments**
3. Attending to **cultural change** and supporting **compassionate communities** approaches

1. **MDT notes accessible to all**
2. **Seamless transitions and data driving redesign** will help real choice
3. Consistent standards of **education** across region

Appendix 2: PRIORITIES FOR TAYPEOLC MCN (MENTIMETER)

1. **IT systems**, fluid transfer of info. communication
2. **Children & Young People (transitions**, complexity)
3. **Co-ordination of care** (key/lead care)
4. **Education** esp. primary care as current GP model is changing (ANP, CN, other providers)

1. **Education** – public and professionals. PEOLC is still often not talked about until its needed
2. **Social care workers being better supported, paid**
3. **Appropriate and timely cascading of information** ie. eHealth improvements, across areas

1. **Transferring learning from malignant to non-malignant disease.**
2. Optimise **communication** at every stage before fear sets in.
3. **Timely referral**

1. **Public health**
2. **Patient journey**
3. **Information sharing**

1. **Communication**
2. **ACP**
3. **User voice**

1. **Listening Platform**
2. **Education** for all
3. **Support** for all

1. **Enabling PPC/PPD choice**
2. **Support and education** for all partners
3. **Improved support and education** around medicine use and safety

1. Ethos of **support and collaborative approach towards staff**

2. More **personalised ACPs** (less tick box)

3. **Geographical alignment of teams** to promote personalised care

1. **Communication and data sharing** across the system
2. **Support person-centred care planning and planning ahead** conversations
3. Straight forward **honest sensitive communications**
4. An **open conversation** about dying including assisted dying