

National End of Life Care programme board, 17th October 2017

Title: Horizon scanning across the sector

Lead:

- Adrienne Betteley, Specialist Advisor for End of Life Care for Macmillan
- Catherine Millington-Sanders, RCGP /Marie Curie National Clinical EoLC Champion, RCGP

Purpose of Paper:

To enable the Board to proactively share intelligence around future opportunities, issues and risks at each meeting thus enabling members to strategically plan and proactively manage these going forward.

The Board is invited to:

- Support the new Hospice UK and NHS Improvement initiative, which focusses on improving the quality and experience of end of life care for people (Adults) accessing emergency care.
- Promote a new resource developed by Together for Short Lives, which supports children's palliative care services to establish and develop a local Family Support Volunteer service, and share details with relevant stakeholders.
- Note the findings published by Marie Curie Palliative Care Research Department at the University College London on inequities in EoLC for people who have dementia and to share the research report with relevant stakeholders.
- Board members are asked to contact the PCG via James Sanderson [james.sanderson@nhs.net] if they would like to input into discussions about extending the legal right around EoLC.

1.0 Risks identified

- No risks identified.

2.0 Opportunities and/or issues to be aware of

2.1 New Hospice UK and NHS Improvement initiative

Raised by: Sherree Fagge, NHS Improvement

- NHS Improvement (NHSI) and Hospice UK are working in partnership to deliver a new initiative which focusses on improving the quality and experience of end of life care for people (Adults) accessing emergency care. The project will focus on: acute admission, improving flow, preventing unwanted hospital admissions, supporting choice, and improving system efficiency.
- NHSI and Hospice UK will work alongside 8 systems (2 per ECIP/NHSI region) to identify 'areas for improvement' over a 12-month period.
- The project will support sites to assess specific improvement needs around EoLC, including: communication, how teams manage clinical uncertainty of recovery in parallel with treating reversible causes of deterioration, access to patient's records, discharge planning and Trust culture. Work will be set within the context of the local system and will align to local priorities.
- Identification of the evidence base and best practice will support this work, together with the use of site analytics (casefile review) to identify any areas of strength and weakness aligned to improving CQC ratings.
- The project will focus specifically on adult patients who maybe in the last months of life, using the Institute for Improvement 15 Step Challenge Fresh Eyes Review and the IHI model for improvement and QI methodology including a 2x2 casefile review.
- Following completion of the project, case studies will be published alongside a rapid improvement guide.

<p>ACTION: Board members are asked to support this Hospice UK/NHSI initiative as it moves forward.</p>

2.2 New web-based resource: 'Together We Can'

Raised by: Shaun Walsh, Together for Short Lives

- There are 49,000 children and young people in the UK with life-limiting or life-threatening conditions, these families are under enormous strain, caring for their child 24/7. A little extra help from a

volunteer at home can make a huge difference to families, helping them to cope better.

- To support this need, Together for Short Lives (T4SL) have published a new web-based resource kit called 'Together We Can'. The resource provides services with a complete easy-to-use set of resources on how to establish and develop a local Family Support Volunteer service.
- The free resource draws on the first-hand experiences of families, volunteers and services from a previous pilot, which explored how volunteers can have a positive impact on the daily lives of these families at home. The 'Together We Can' resource can be downloaded from: www.togetherforshortlives.org.uk/togetherwecan.

<p>ACTION: Board members are asked to promote the new resource and share details with relevant stakeholders.</p>

2.2 Research findings on EoLC patients with dementia

Raised by: Jane Collins, Marie Curie

- Researchers from the Marie Curie Palliative Care Research Department at University College London have published a research paper on a study which found that people in the later stages of dementia receive most of their healthcare from GPs or emergency services, with little support from specialist healthcare professionals, despite having complex needs.
- The research found that only 1% of people with advanced dementia were seen by a geriatrician or an older persons' psychiatrist and that 96% of people in the study saw a GP in their last month of life. The study also concluded that paramedics play a major role in assessment and healthcare towards the end of life, suggesting a reactive rather than planned response to patients' needs – nearly one in five (19%) were seen by a paramedic in the month prior to their death.
- Care homes, where the majority of people with dementia will die, were also found to be poorly served by secondary healthcare services and GPs visiting homes were not supported by specialist services. Palliative care teams may have assisted with symptom management but less than a third of participants (28%) were seen by a palliative care team (34% were referred) and this was predominantly in the month prior to their death.
- Based on the findings, the researchers say that healthcare services are not currently tailored to the complex needs and symptoms of people with advanced dementia. Given that dementia is now the leading cause of death, they say there is urgent need to ensure an adequate standard of comfort and quality of life for patients.

ACTION: Board members are asked to take note of the findings and to share the research with relevant stakeholders. The full research paper can be found at:

<http://journals.sagepub.com/doi/full/10.1177/0269216317726443>

2.3 Extending legal rights in EoLC

Raised by: James Sanderson, NHS England

- NHS England's Personalised Care Group (PCG) and the Department of Health are currently exploring extending legal rights to choice, personal health budgets and integrated personal budgets and are planning a public consultation later this year. As part of this work the team are considering extending legal rights to include some aspects of EoLC, in line with the EoL Commitments.
- NHS England's EoLC team will be working with the PCG to draft suitable wording to be included in the consultation and are keen to have the Board's involvement in those discussions.

ACTION: Board members are asked to contact the PCG via James Sanderson [james.sanderson@nhs.net] if they would like to input into those discussions.