

Addressing Inequalities at the end of life

2021/21 series Evaluation

'Dying is a universal part of life's journey, and every individual will experience it in a different way' stated *David Behan, (Former) Chief Executive, Care Quality Commission* in the foreword of the 2016 CQC report entitled 'A Different Ending'.

The CQC report was undertaken to highlight the challenges which are faced by inequality groups when access to appropriate palliative and end of life care is required. The report found that where commissioners and leaders worked together with an equality and individualised approach, end of life services were more responsive to individual needs and people received better care. However, the report also concluded that although some localities are already doing this, many are not. This leads to mixed experiences at the end of life, for the person and those close to them.

Key Findings (*'A Different Ending' CQC 2016*)

KEY FINDINGS

- Each of the groups we looked at, and individuals within them, have unique needs and considerations. Lack of understanding about these is a significant barrier to people receiving good, personalised care.
- Difficulty in identifying the last 12 months of life for people who have conditions other than cancer, including frailty and dementia, means that conversations about end of life care do not always happen early enough. Talking about end of life care as part of wider care and treatment enables people to plan and make choices about their care.
- It can be challenging for health and care staff to communicate well about end of life care, particularly when the person's prognosis is uncertain. Commissioners and providers should make sure that health and care staff have good communication skills and the right support to meet people's individual communication needs.
- Access to the right end of life care services, such as hospices, is difficult for people from some groups. Everyone should be able to access the right care at the right time in response to their individual needs and preferences.
- The end of life care needs of some people, including people with a mental health condition, people with a learning disability, people who are homeless, and Gypsies and Travellers, are particularly overlooked. This may be because they are often excluded from wider health services. Improving access to services for socially excluded groups, including access to end of life care services, needs to be a priority.

The Greater Manchester and Eastern Cheshire Strategic Clinical Network (GMEC SCN) are committed to promote a health and care system which ensures that the systems in place can deliver inclusive, personalised, and compassionate care in all care settings during the last phase of life.

High quality personalised and inclusive end of life care is every one's business and no one individual or group of people should be left behind. We work collaboratively to ensure delivery improvements take place so that everyone receives the care they should be able to expect at the end of their life.

The Inequalities series 2020/21 was designed to raise awareness of the challenges faced by inequality groups, to share best practice and current available guidance and to facilitate collaboration and discussion amongst delegates.

During the 2020/21 sessions the following areas were reviewed:

- Homeless people
- People who use substances (SUAB)
- Primary Care Services/ Hospice care and Chaplaincy & Spiritual care
- Specialist bereavement services (Suicide)
- People living with dementia
- People with conditions other than cancer
- People with mental health conditions
- People in detained settings (Prisoners)
- Black, Asian and minority ethnic groups (BAME)
- People from the LGBTQ+ community
- People with learning disabilities
- The role of personalised care

To develop the series small task and finish group was formed and chaired by the Strategic Clinical Networks which included the membership below:

Name	Organisation
Shelley Cunliffe	Quality Improvement Project Officer, Palliative and End of Life Care
Elaine Parkin	Quality Improvement Programme Manager Palliative and End of Life Care
Christine Taylor	Quality Improvement Senior Project Manager Palliative and End of Life Care
Denise Woolrich	Business Support Officer, Palliative & End of Life Care
Dr Liam Hosie	GP and Primary Care Clinical Lead, GMEC Strategic Clinical Network
Jane Ashworth	Springhill Hospice Specialist Palliative Care Education Lead
Jude Holt	St Ann's Hospice Specialist Palliative Care Education Lead
Mark Donaghy	Greater Manchester SCN Communications Lead
Michelle Davies	Greater Manchester Events Manager

There were clear objectives to this project:

- To raise awareness and better understand the challenges faced by individuals and groups of people who may have experienced inequality and use that as an educational tool which increases understanding of community needs and stimulates discussion and quality improvements within localities.
- To align with the National Ambitions for Palliative and End of Life Care, particularly Ambition number six which states 'Each community is prepared to care'.
- To complement and align with The Greater Manchester Commitments, particularly that the care a patient received towards the end of life is individualised, skilfully and sensitively delivered and of a consistently high standard. The Greater Manchester Commitments support individual choice in line with the Care Act.

Following consultation with our Clinical Leaders the project proposal was discussed at the GMEC Educators Network in order to establish needs and recruit expert assistance onto formation of the project plan.

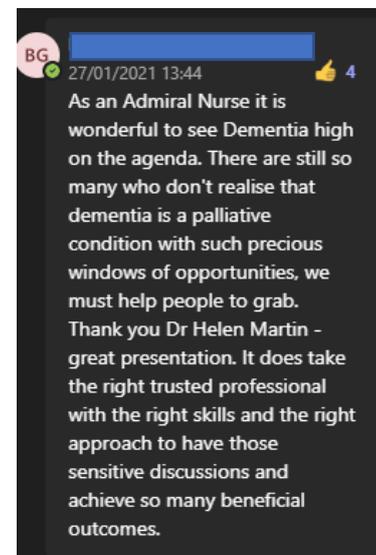
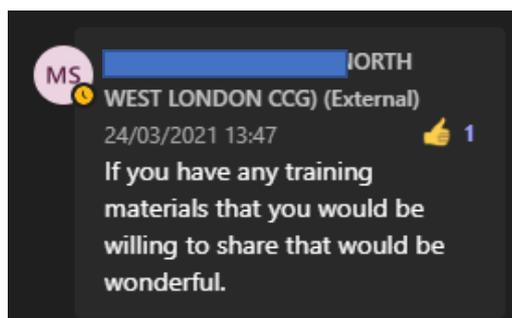
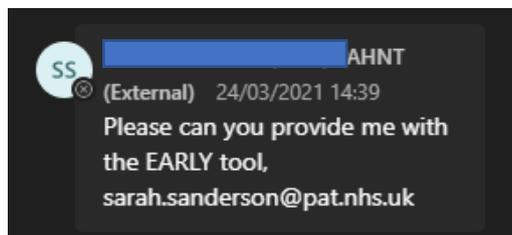
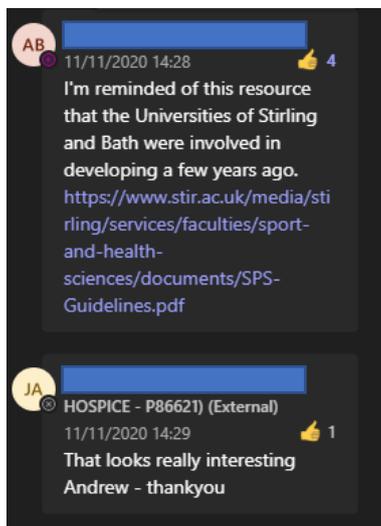
An initial task and finish group was formed which included experts from each of the inequality groups and work took place to identify key quality improvement needs for each group. The SCN team also asked that each expert include and discuss the need for appropriate Identification Advance Care Planning (ACP), and coordination of care within each of the inequality areas. These three elements of care aligned to the Greater Manchester and Eastern Cheshire draft framework for palliative and end of life care

Following this the experts then collaborated with their own colleagues in developing educational sessions which would last approximately 40 minutes each. 6 sessions of 2 hours were planned monthly to run virtually from November 2020 until April 2021. A comprehensive project plan was developed, rehearsal opportunities provided, and communication plan initiated.

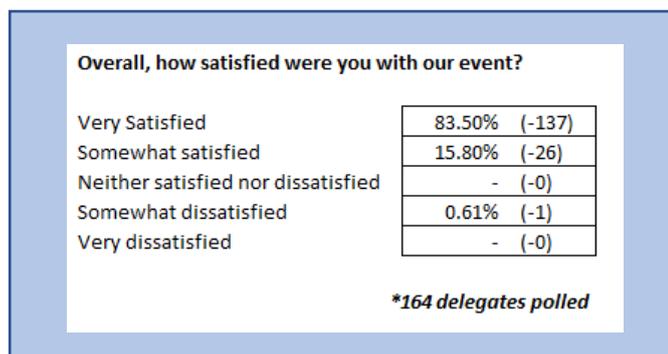
The project team work collaboratively with localities to build upon working relationships, promote open discussion around best practice and quality improvement, and generate approaches that will support the GMEC population. Through the Greater Manchester and Eastern Cheshire Strategic Clinical Network (GMEC SCN) Educator Network, community contacts and NHSE/I events promotion the Inequalities series was promoted **across NHS England**.

Event Date	Subject	Attendance
Nov-20	Homelessness	147
Nov-20	SUAB	147
Dec-20	Primary Care	97
Dec-20	Bereavement/ Suicide	97
Jan-21	Dementia	104
Jan-21	Conditions other than Cancer	93
Feb-21	Mental Health	91
Feb-21	Prisoners	82
Mar-21	BAME	135
Mar-21	Personalised Care	124
Apr-21	LGBTQ+	155
Apr-21	Learning Disabilities	141
TOTAL ATTENDANCE		1413

The events provided an excellent opportunity for collaborative working and information exchange as was witnessed within the live discussion threads:



The importance of Advance Care Planning (ACP) ran through the events to highlight the benefits of discussing future wishes and priorities for care with family and friends. Overall, 99.3% of evaluations submitted reported that they were satisfied/very satisfied with the inequality events with some positive feedback and general comments received:



Sample feedback received:

Responses to the events were largely positive. The project team worked together to deliver a high quality, well organised and sensitive campaign which highlighted the importance of tackling inequality in Palliative and End of Life care and discussed some of the resources available to assist health and care professionals in service quality improvements.

I know COVID has forced online presentations, but I think u should consider this way of delivering in the future as well. The attendance today from all over the UK supports this.

I think this was an amazing session, so helpful. Wish it could have been longer. I am hoping even when restrictions stop you will continue to do online workshops like this so people from all over the country can attend.

Please repeat this Inequalities series! from a selfish perspective there are sessions this time I'm unavailable to attend and also have colleagues who I think would find them helpful and interesting

Recommendations:

Following a review of feedback received the project team have made the following recommendations:

1. The Project Team were disappointed that we were unable to secure a session dedicated to the travelling community at this time. A concentrated effort should be made to understand health & care provision preferences of the travelling communities across the area.
2. The emphasis on a Personalised Care and Support Approach to Palliative and End of Life Care should be reinforced across all health and care staff particularly when providing care from those individuals belonging to any of the inequality groups.



NHS_Support
Conversation_LRPRC

3. Production of a permanent educational resource for health and care staff to access which raises awareness of each inequality group and how to access further resources and advice in relation to Palliative and End of Life Care.
4. Consider repetition of event series in the future.

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