



The National End of Life Care Intelligence Network (NEoLCIN) was established in 2010 to improve the data and intelligence available to support the NHS and its partners commission and deliver quality end of life care. This update provides a summary of activity across the network over the last year.

Contents

Our first year in PHE	1
Reports and resources	2
Partnership reports	2
Journal articles	3
Data and intelligence support	3
Supporting quality and improvement	3
Events	3
Website	4
Consultation and evaluation	4
Who's who in the network team?	4
Contact us	4

Our first year in PHE

On 1 April 2013, the network moved into **Public Health England** (PHE), an executive agency of the Department of Health. It is one of five health intelligence networks in the **Chief Knowledge Officer's directorate**.

As a health intelligence network, we operate across organisations bringing together various holders of information, national charities, NHS partners, researchers and key users of health intelligence.

Moving into a new organisation, bringing together around 100 organisations and fitting into new structures and ways of working, was both challenging and exciting. We have been able to benefit from new opportunities and the range of expertise within PHE.

We have published a number of new reports and resources this year to support stakeholders and extend the knowledge and evidence base for end of life care. We have also been involved in other activities through which we have engaged with partners and communicated the value of the network.

Reports and resources

What we know now 2013 our annual collation of new end of life care data and intelligence, summarising key findings of the network and partners over the last year.

Electronic Palliative Care Co-ordination Systems (EPaCCS) in England presents the results of a national survey of clinical commissioning groups (CCGs) to gather information about EPaCCS implementation since 2012. It includes information about systems and approaches being used and shares the learning and experiences of implementers.

End of life care profiles for clinical commissioning groups the first time we have published end of life care profiles for CCGs. The profiles draw together a wide range of information to give an overview of variations in cause and place of death, by age and sex, for each CCG in England.

National information standard and guidance we worked with partners to update the specification for the national information standard for end of life care co-ordination and the associated record keeping and implementation guidance. The standard identifies and defines the core content to be held in EPaCCS, enabling the recording and sharing of people's care preferences and supporting better co-ordination of services.

Classification of place of death a short technical bulletin explaining how we classify place of death from death certificate data recorded by the Office for National Statistics.

Patterns of end of life care in England presents high level trends designed primarily to give PHE region and centre colleagues an overview of data about deaths in their areas. It focuses on the main indicators used in the **end of life care local authority profiles** and highlights geographical variations.

Proportion of deaths in usual place of residence we continue to report the proportion of deaths in usual place of residence – a proxy indicator for quality of end of life care. Quarterly figures are provided for each CCG, area team and strategic clinical network in England.

Partnership reports

Palliative and end of life care for Black, Asian and minority ethnic (BAME) groups in the UK with Marie Curie Cancer Care. Presents a systematic review of the literature and makes recommendations for improving end of life care for BAME groups.

National survey of patient activity data for specialist palliative care services with the National Council for Palliative Care. This report provides valuable insight into the care provided by this sector.

Journal articles

Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010. *BMC Neurology*. Volume 14: 59. March 2014.

How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*. Volume 28 Issue 1, January 2014.

Supporting care integration with Electronic Palliative Care Co-ordination Systems (EPaCCS). *International Journal of Palliative Nursing*. February 2014.

Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone disease, and multiple sclerosis: a population-based study. *Palliative Medicine*. Volume 27 Issue 9, October 2013.

The End of Life Care Quality Assessment (ELCQuA) tool: a free online resource for health and social care professionals. *European Journal of Palliative Care*. July/August 2013.

Data and intelligence support

NEoLCIN responds to enquiries and requests for data and analytical support from local teams, partners and other stakeholders. This year we responded to approximately 100 enquiries.

Supporting quality and improvement

ELCQuA (End of Life Care Quality Assessment Tool) is a freely available, online quality assessment tool to support commissioners and providers. The tool was migrated onto PHE servers this year and some improvements have been made to better support users. We held a successful WebEx training session in February 2014 which was targeted at the hospice sector and we were supported by colleagues in Help the Hospices.

The network has supported the two priority programmes in NHS Improving Quality: **Electronic Palliative Care Co-ordination Systems (EPaCCS)** and **Transform Programme** to improve end of life care in acute hospitals. We carried out a national survey of CCGs in England to determine implementation of EPaCCS and we have supported the Transform programme with collection and analysis and reporting of metrics to track the impact of the programme.

Events

Routinely collected data can make a major contribution to understanding ways to improve palliative and end of life care, yet they are often an underused resource. We

held a series of four research symposia this year, bringing together national and international researchers and other data users to consider how best to use routine data and to support international collaboration. The symposia focused on the specific areas of neurological disease, dementia and physical frailty, cancer and methodology.

We have made over 20 oral and poster presentations at national and international conferences during the year including the **National Cancer Intelligence Network's Cancer Outcomes 2013** conference.

Website

We continue to promote the use of data and intelligence through our website www.endoflifecare-intelligence.org.uk, where all of our resources are freely available.

Consultation and evaluation

We have consulted with stakeholders to evaluate the network's impact and to inform future plans. We will be publishing a summary report shortly. The key messages are encouraging: the network is felt to be making a difference and we are achieving against our stated functions. There were some recommendations for improvements, which we are currently reviewing.

Who's who in the network team?



Professor Julia Verne is the clinical lead for the network and provides expertise and guidance on several national groups for end of life care. Julia is supported by a small team of analysts based in the PHE's Knowledge and Intelligence Team (South West).



Katie Lindsey (left) is the network's programme manager.

Kerry Archer-Dutton (right) is the network's programme administrator.

Contact us

If you would like to contact us, give feedback on our activities and outputs, make a data request, or ask for further information, please email neolcin@phe.gov.uk.