National End of Life Care Intelligence Network

Response to our consultation and what we will do

Follow up from the impact evaluation of NEoLCIN

About Public Health England

Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

The National End of Life Care Intelligence Network (NEoLCIN)

The National End of Life Care Strategy published in 2008 pledged to commission a National End of Life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England. The network was established in May 2010. Its aim is to support the NHS and its partners to commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. The NEoLCIN plays a vital role in supporting delivery of the strategy. On 1 April 2013 the NEoLCIN became part of Public Health England.

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Introduction and background

The National End of Life Care Intelligence Network (NEoLCIN) is now part of Public Health England (PHE), an executive agency of the Department of Health, and sits within the Chief Knowledge Officer Directorate.

One of the outcomes from the 2008 National End of Life Care strategy was the commissioning of the network in 2010 to improve the collection and analysis of national data about end of life care for adults. 2013 was a transitional year for the network when it moved to PHE on 1 April from its original hosting organisation. The network's executive team, with support from PHE, decided that it was an opportune time to evaluate the work and impact of the network to inform future business planning and ensure that the original model of working and ambitions for the network are still relevant and fit within the new health and social care infrastructure.

During February and March 2014 views were sought from a wide range of users and stakeholders on the perceptions, resources and the impact the network has made since being commissioned. The evaluation consisted of three parts – an online survey sent out to around 1600 people but freely accessible through the PHE and network's websites, interviews with 12 members of the external stakeholder group and analysis of the website usage.

The evaluation findings have been published in separate report published alongside this document, National End of Life Care Intelligence Network: Impact Evaluation. Overall the network is well thought of and supported and all those taking part believed the data and information provided by the network had made a difference. There were some suggestions for improvement and the main themes are:

- improve clarity of NEoLCIN role and function
- raising awareness, our/profile and communications
- better access and timeliness of data
- provision of guidance on use of the data and intelligence
- improve website

These recommendations have been considered by both the external stakeholder advisory group and the executive team and this document lays out our response. We are very grateful to all who participated in the consultation and welcome continued dialogue and feedback on our performance.

2 Improve clarity of NEoLCIN role and function

What is already in place

The 'About us' section on NEoLCIN website provides information on the role and objectives.

'About us' information is included in all publications.

We will do…our plans

Add the following seven summary functions to the website:
1. Provision of data and intelligence to support quality improvement
2. Provision of data and intelligence to support best use of resources
3. Sharing of best practice
4. Provision of evidence to guide delivery of care
5. Working with partners to develop best practice in end of life care
6. Supporting stakeholders to make best use of the data and intelligence available
7. Working towards improved national data about end of life care

Review and update our web pages to ensure that we are clear about what we can and can't do and to sign post to local data sources.

Review and update the 'About us' information in our publications.

Look for opportunities to promote NEoLCIN and embed messages within wider agendas, for example long term conditions, dignity, safety and information sharing.

Keep NEoLCIN's role and function under review and respond to changing need.

3 Raising awareness, our profile and communications

What is already in place

A communication plan is put in place for each new publication/resource.

Provide regular e-alerts to update those on mailing list/

NEoLCIN is included on the PHE Knowledge Portal.

A link to NEoLCIN from the Centre for End of Life Studies (CELS) website for end of life care facilitators and social care champions.

Produce media releases for new publications/resources. Example Deaths from Cardiovascular Disease Report.

Publication of articles in academic journals. Example from European Journal of Palliative Care.

NEoLCIN is represented on numerous national committees/steering groups, research project advisory groups.

Presentations at a number of national and international conferences Example National Cancer Intelligence Network's conference 2014.

Disseminate message using PHE communication channels and the PHE national Twitter account @PHE_uk.

Disseminate messages via our partner organisations.

We will do…our plans

New communications strategy for NEoLCIN within the Health Intelligence Networks in Public Health England is being developed.

Plan an engagement programme to support stakeholders.

Identify opportunities to better promote messages through our stakeholders' networks.

Consider options for disseminating messages and look to provide a range of targeted approaches.

Investigate opportunities to improve use of social media.

Continue to engage with users, inviting feedback and carrying out regular surveys to determine data and intelligence needs.

Repeat the stakeholder survey in 2015 and promote the survey more widely.

Encourage more people to sign up to e-alerts by promoting this at events.

4   Better access and timeliness of data

What is already in place

New End of Life Care profiles (2012 data) for each CCG in England were published April 2014.

The 'What we know now' publication provides a compilation of new information and evidence produced over the past year by NEoLCIN and its partners, a new compilation will be available in Autumn 2014.

Quarterly figures on the proportion of deaths in usual place of residence are published on the website approximately 5 months after the end of each quarter. This data is presented for each CCG, strategic clinical network, area team and for England.

We will do…our plans

Update CCG and LA profiles with latest available data on an annual basis whenever possible.

Publish new profiles for acute hospital trusts in England by March 2015.

Aim to publish more timely reports to best support stakeholders.

Explore opportunities for signposting stakeholders to new evidence and information.

Investigate the current availability of local data and identify any opportunity to support/influence timely provision.

5 Provision of guidance on use of the data and intelligence – respond to the *so what?* question, extend its usage

What is already in place

A user guide for end of life care profiles and metadata guides are published on website to support users.

South West Knowledge and Intelligence Team provide guidance and support service to stakeholders and local teams on request.

NEoLCIN provides expertise, analytical and data collection support for NHS Improving Quality's *Electronic Palliative Care Co-ordination Systems* (EPaCCS) and *Transform Acute Hospitals* improvement projects.

We will do…our plans

Plan an engagement programme which will include presentations to the end of life care facilitators and social care champions and to the end of life and specialist palliative care network leads in June 2014.

Consider additional master classes, podcasts or WebEx seminars.

Publish case studies to illustrate use of data for commissioners, providers and clinicians.

Continue to embed NEoLCIN data and intelligence in end of life care improvement work.

6 Improve website

What is already in place

Website is hosted by South West Knowledge and Intelligence Team (SW KIT) but content will be moved PHE's .gov.uk website as part of PHE's digital strategy.

We will do…our plans

Improve layout of webpages to facilitate access to resources.

Update with new content as it becomes available.

Remove broken links and old content.

Engage in plans for transition of content to .gov.uk and ensure user needs addressed.