Public Health England

National End of Life Care Intelligence Network

Impact evaluation

Results of the 2014 evaluation of the work and impact of the network.

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.

This document is available in other formats on request. Please call 020 8327 7018 or email publications@phe.gov.uk

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Executive summary

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 is now 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 people from the external stakeholder group and analysis of the website usage. The main body of the report looks at the results in depth but the key results are highlighted below.

Summary of results from the online survey

The survey asked people to rate the impact the network has made since being commissioned in 2010. Chart A shows the responses. Over 50% rated the network as having a positive impact across all categories, and only five out of an average of 253 people responded that it had made a negative impact.

Chart A – Impact
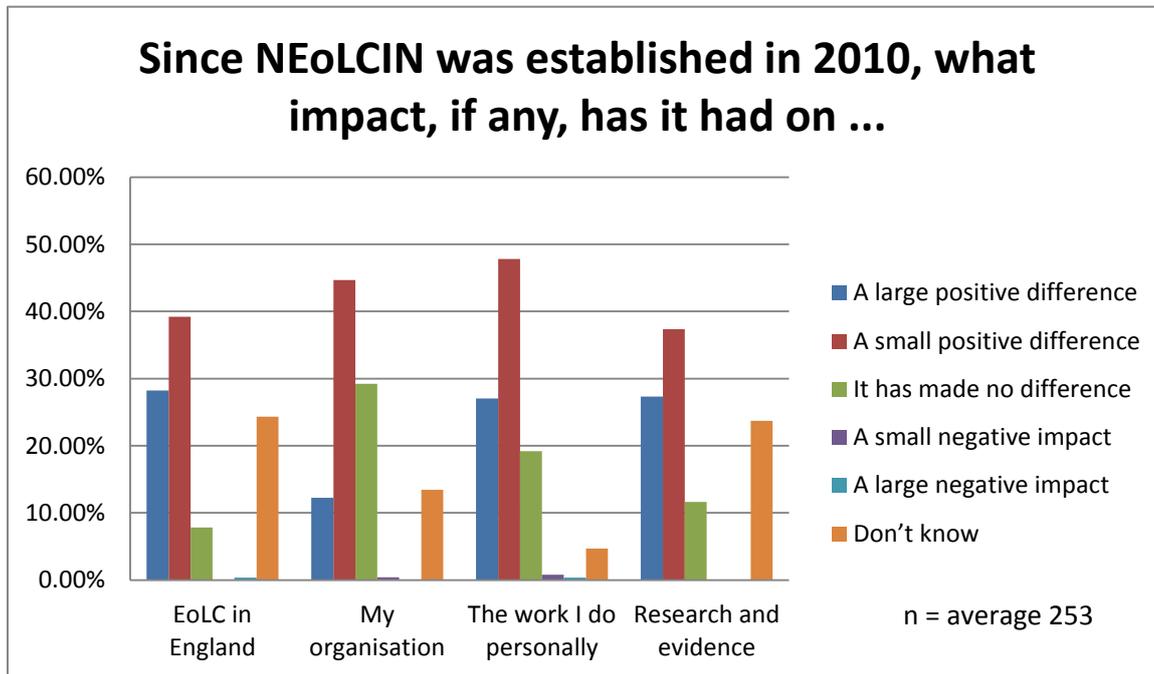
Other key results are:

73% believe they understood the role of the network fairly well or very well.

The survey asked two questions related to the seven functions undertaken by the network – these are:

- provision of data and intelligence to support quality improvement
- provision of data and intelligence to support best use of resources
- sharing of best practice
- provision of evidence to guide delivery of care
- working with partners to develop best practice in end of life care
- supporting stakeholders to make best use of the data and intelligence available
- working towards improved national data about end of life care

When the seven function's ratings are grouped together an average of 77% rated the network's performance as 'average' (23%), 'above average' (38%) or 'excellent' (16%).

When ratings for the seven functions are grouped together an average of 92% rated the importance of the network performing the functions as 'very important' (68%) or 'important' (24%) with 'working towards improved national data about end of life care' receiving the highest 'very important' rating at 79%.

60% said they would speak highly about the network, a third responded they would be neutral, and six out of 255 people said they would be critical.

39% of 243 people responding said they had visited the website within the last month and 12% within the last week. 13% said they could not remember or had never visited the site.

An average of 64% rated the seven resources listed as useful or very useful. A significant minority (28%) did not know or had not used the resources, and on individual ratings nearly 18% rated ELCQuA as not very useful/not useful.

67% of the 243 people who responded said they were either very confident or confident when using the network's resources.

When asked to provide an overall rating of the resources against five criteria a majority thought they were all above average or excellent. Being 'relevant and useful' was rated by 70% as above average or excellent, and being 'timely' received 55% which was the lowest but still good.

Two questions were available requiring free text responses, the themes emerging were:

Q What advice would you give NEoLCIN to help it improve over the coming year?

Raise the profile and work more closely with stakeholders and partners.

Look beyond usual stakeholders and engage more with those on the ground and listen to what they want.

Improve availability and make data more up to date – provide more narrative and tell the story – reduce complexity and increase compatibility.

Provide a clear message on what your role and function is – don't duplicate the work of other end of life care organisations, align with care priorities.

Make website more user friendly.

Q Please tell us what else you would like to see provided by NEoLCIN and any suggestions on improving our publications and resources?

Keep people informed.

Easily interpreted up to date data sets.

Improve data compatibility.

Tell us what has worked elsewhere.

Three questions within the online survey referred to use of the website and when combined with the evaluation of usage of the website it showed that 76% of those responding found what they were looking for when accessing the website, and the 'What we know now' series of publications were the most popular download.

Of the people completing the survey and who provided information on the nature of their work, 52% were from within the NHS, with the voluntary sector coming second highest at 20% and only 7% came from social care.

Summary of results from the stakeholder interviews

Overall the network is well thought of and supported, and all of those taking part in the interviews believed data and information provided by the network had made a difference. The stakeholders provided constructive comments underpinning their commitment to enable the network to go from strength to strength and to secure its future.

The emerging themes were around:

- raising awareness
- confidence and timeliness of data
- partnership working
- role and focus
- the stakeholder group and resources

These themes are compatible with the results from the free text comments on the online survey and considered further within the conclusions section of the main report.

Summary of conclusions

Overall between 250 and 300 people took part in the evaluation and the majority of responses across all areas should be interpreted as positive, with only a small minority giving negative feedback. However, a significant minority of responses reflected that people either did not know enough to form an opinion or had not used the resources. It was evident that a number of themes recurred across both survey methodology, which would suggest that the sample size was sufficient for the evaluation to be reliable.

With the backing of PHE as a credible and nationally recognised organisation, and engagement with the research community, the network is well placed to become more widely acknowledged as a reliable centre of expertise across sectors. The challenge for the network and PHE is likely to be managing the expectations of those who have suggested an expanded role for the network, and the feasibility and options for delivery within finite resources, both financially and the availability of data.

The common themes that should be considered by the executive team when planning future priorities are:

- the network must be clear on its role and function, raise awareness by communicating this more widely across sectors, keep people informed and do not duplicate the role of other end of life care focussed organisations

- it should build on the goodwill it has garnered and extend partnership working, as a clear willingness exists to work with the network from organisations and individuals

- whilst a significant number of people expressed a need for more localised data, and widening the scope, the network must be realistic about its ability to meet that need

- to meet the network's aim of supporting NHS England, CCGs, HWBs and LAs to make strategic planning judgements and assessments at national and local level, the data has to be up to date and issues around data incompatibility need to be resolved

- the network needs to respond to the 'so what' question, by providing more narrative, reducing complexity and help to make best use of data and information if it is to extend its usage

- the website and communications generally need to be reviewed and updated in light of the comments received

1 Introduction

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. The network works closely with the PHE South West Knowledge and Intelligence Team, and its primary role is to collate nationally available data and information on end of life care and transform it into intelligence presented in a usable format for policy makers, commissioners, service providers, researchers and the public.

The network was established in 2010, and in the last three years has become recognised as a leading national and international source of information on where, how and why people die in England. There has been a significant increase in the knowledge, understanding and attitude around end of life care services of those both receiving and delivering services due to the work of the network with the partnerships it has formed.

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 is now 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 2010. This report provides the results of the evaluation project.

2 Background

The national End of Life Care Strategy, published in July 2008, aimed to improve the quality of care for all adults at the end of life regardless of their condition, and provide them with more choice about the care that they receive. One of the outcomes from the strategy was the commissioning of the National End of Life Care Intelligence Network in 2010 to improve the collection and analysis of national data about end of life care for adults.

Originally the network was hosted by the National End of Life Care Programme and due to organisational change transferred to Public Health England (PHE) on 1 April 2013. This has provided new opportunities for partnership working as well extending the scope to support and share intelligence and data with a wider group of organisations. Plans are also in place to refresh the 2008 End of Life Care Strategy in 2014 (working title 'Ambitions for end of life care') and the network will be working closely with the National Clinical Director for end of life care to identify and collate new and improved data sets and intelligence for the future.

The network works with a wide range of existing partners with an interest in improving end of life care and an external stakeholder advisory group comprising of partner organisations, researchers and others interested in using information to improve end of life care has been established to direct and guide its work.

The network aims to provide data and intelligence to support health and social care commissioners and service providers across statutory and voluntary sectors, 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.

3 Evaluation methodology and limitations

The evaluation will be used to inform PHE on the achievements, benefits, challenges and impact the network has made, and provides direction for future work and priorities. The evaluation was undertaken in three parts.

Online Survey

The survey was live during February 2014 with a closing date of 28th February. It comprised of 19 questions and was a mix of rated responses to statements, and questions requiring free text answers.

The link was sent to approximately 1600 people including:

- those signed up to receive email alerts from the network
- End of Life Care Quality Assessment (ELCQuA) tool users
- members of the original stakeholder group

NHS Improving Quality (NHS IQ) circulated the link to the end of life care facilitators and champions network, trusts taking part in the transform hospitals programme, as well as

members of the Electronic Palliative Care Co-ordination Systems (EPaCCS) group. Association for Palliative Medicine circulated it to their members, and the survey was accessible from both the PHE and NEoLCIN websites.

People completing the survey were asked to provide information about their work or involvement in end of life care and 237 people provided information. 52% (122) came from the NHS with the voluntary sector coming second highest with 20%. Only 7% (17) came from social care. (See Chart 11 for full breakdown).

In depth interviews with members of the external stakeholder group

In-depth interview methodology with a small group of stakeholders was used to gather more detailed information and provide context to the other two elements of the evaluation, the online survey and analysis of website usage. This methodology is generally used to gain the perspective of individuals on a particular idea, programme or situation and replace focus groups where constraints may be on time available to bring key individuals together, or in more sensitive situations individuals may not feel able to speak openly in a group setting. For the network the former was the deciding factor.

The stakeholders invited to contribute, and the six discussion topic areas, were identified and agreed by the PHE NEoLCIN Programme Manager and the executive team. An independent contractor was commissioned to undertake the interviews. Potential time constraints for a number of stakeholders were identified resulting in each interview scheduled to take between 30 and 45 minutes. The target of 12 interviews was achieved, and conducted during February and early March 2014.

Website analysis

Information on the number of visits over the four years since the network was commissioned were collected. Information on the most popular reports to be downloaded and the specific pages and tools accessed were also reported.

Limitations and assumptions

In all cases the views expressed and the ratings given reflect the personal views of those responding and not the organisations or groups they represent. Some of the changes and improvements suggested from the evaluation results may reflect work that is already being undertaken by the network in the areas highlighted. However, these comments should be seen as an indicator that the level of understanding amongst the users and stakeholders might not be as extensive as had originally been assumed.

4 Evaluation results – online survey

4.1 Online survey – rated questions

The numbers of people who responded to each question is included, however not all people answered all the questions.

Key results:

73% believe they understood the role of the network fairly well or very well

When ratings from the seven listed functions undertaken by the network are grouped together an average of 77% rated the network's performance as 'average' (23%), 'above average' (38%) or 'excellent' (16%).

When ratings from the seven listed functions are grouped together an average of 92% rated the importance of the network performing the functions as 'very important' (68%) or 'important' (24%).

60% said they would speak highly about the network, a third responded they would be neutral, and six out of 255 people said they would be critical.

Over 50% rated the network as having a positive impact on end of life care services, the work they do and the organisation they are within.

39% of the 243 people said they had visited the website within the last month and 12% within the last week. 13% said they could not remember or had never visited the site. 75% said they had found what they were looking for on the website.

An average of 64% rated the seven resources listed as useful or very useful. A significant minority (28%) did not know or had not used the resources, and on individual ratings nearly 18% (40) rated ELCQuA as not very useful/not useful.

67% of the 243 people who responded said they were either very confident or confident when using the network's resources.

When asked to provide an overall rating of the resources against five criteria a majority thought they were all above average or excellent. Being 'relevant and useful' was rated by 70% as above average or excellent and the rating against 'timely' was the lowest at 55%.

a) Understanding the role of the network

Out of 263 people who responded to the question, 73% said that they understood the network's role fairly well/very well with two people (1%) answering 'don't know' and the

remaining 26% understanding the role not very well or not at all well. Chart 1 shows the detailed results.

Chart 1 – Understanding the role of the network
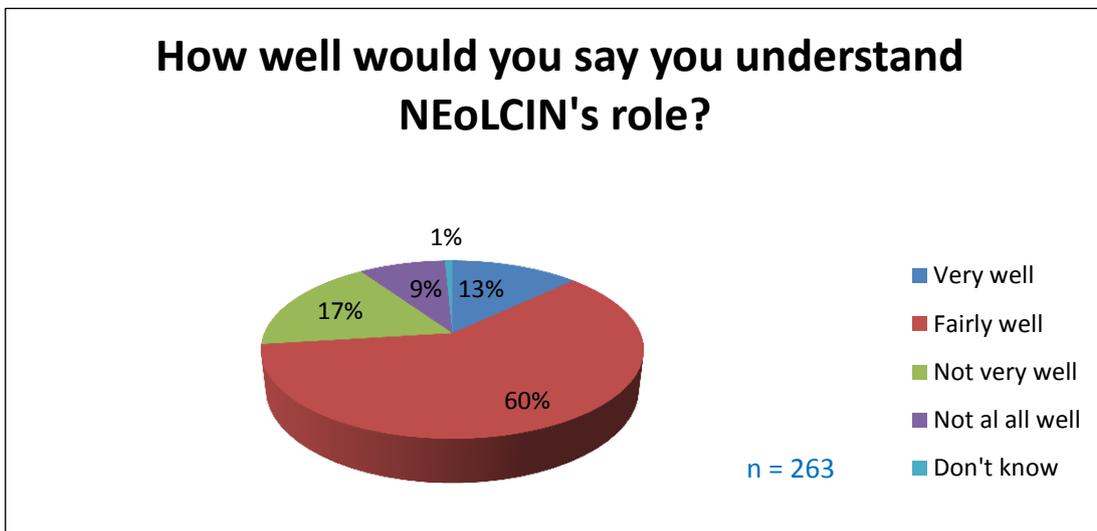
b)   Functions

The survey asked two questions related to how well the network performed a list of seven functions and how important it is for the network to perform the functions. Charts 2 and 4 show an average value for responses to all seven functions and Tables 1 and 2, Charts 3 and 5 show the detailed responses against each of the functions. An average of 255 people rated each function across the two questions.

Each of the seven functions received over 70% of responses rating the performance of the network as average or above. The importance of the network providing each of the functions was rated by over 85% as important/very important. The main results for each of the functions using the top two positive rating categories for each question are:

Providing data and intelligence to support quality improvement

Of those who responded 64% rated the performance as above average or excellent, and 95% said that it was important/very important for the network to perform the function.

Providing data and intelligence to support best use of resources

54% rated the performance as above average or excellent, 95% said it was important/very important for the network to perform the function.

Sharing best practice

53% rated the performance as above average or excellent, 90% said it was important/very important for the network to perform the function.

Providing evidence to guide delivery of care

50% rated the performance as above average or excellent, 92% said it was important/very important for the network to perform the function.

Working with partners to provide best practice in end of life care

46% rated the performance as above average or excellent, 87% said it was important/very important for the network to perform the function.

Supporting stakeholders to make best use of the data and intelligence available

42% rated the performance as above average or excellent, 94% said it was important/very important.

Working towards improved national data about end of life care

66% rated the performance as above average or excellent, 96% said it was important/very important.
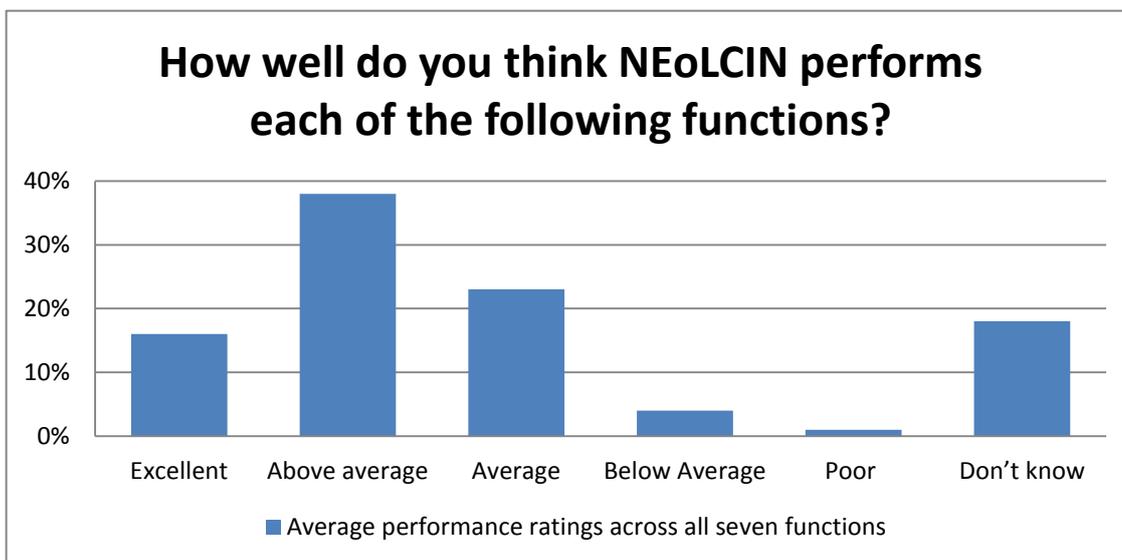
Chart 2 – Performance rating

Table 1 – How well do you think NEoLCIN performs each of the following functions:

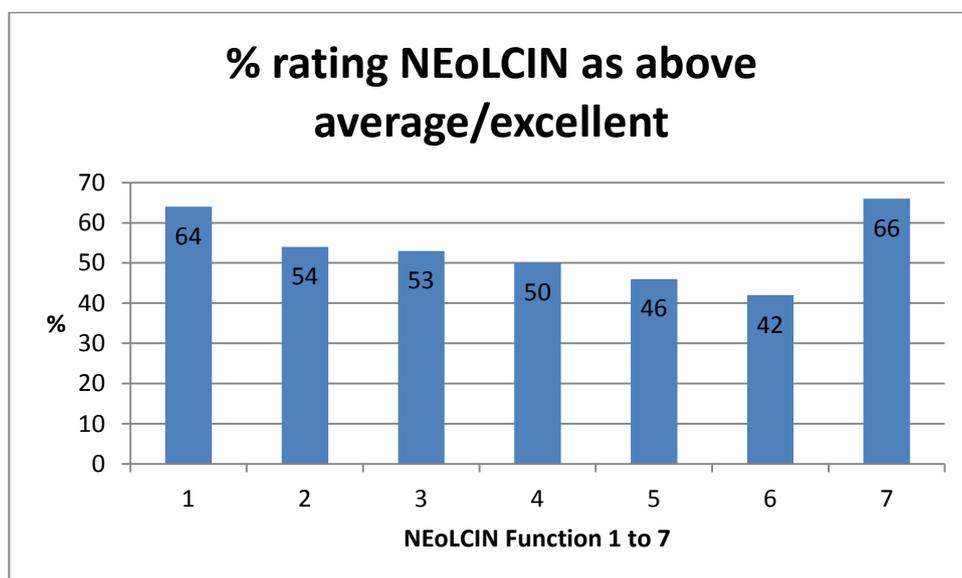|	Excellent	Above average	Average	Below average	Poor	Don't know	Response Total
Provision of data and intelligence to support quality improvement	18.29% (47)	45.91% (118)	16.73% (43)	1.95% (5)	0.78% (2)	16.34% (42)	257
Provision of data and intelligence to support best use of resources	13.67% (35)	40.23% (103)	24.22% (62)	1.56% (4)	0.78% (2)	19.53% (50)	256
Sharing of best practice	15.23% (39)	37.5% (96)	22.66% (58)	5.47% (14)	0.78% (2)	18.36% (47)	256
Provision of evidence to guide delivery of care	15.18% (39)	35.41% (91)	23.35% (60)	5.06% (13)	0.78% (2)	20.23% (52)	257
Working with partners to develop best practice in end of life care	12.6% (32)	33.86% (86)	26.77% (68)	5.51% (14)	1.57% (4)	19.69% (50)	254
Supporting stakeholders to make best use of the data and intelligence available	11.86% (30)	30.43% (77)	29.64% (75)	7.11% (18)	1.58% (4)	19.37% (49)	253
Working towards improved national data about end of life care	25.2% (64)	40.94% (104)	16.54% (42)	2.76% (7)	0% (0)	14.57% (37)	254

Chart 3 – Individual function performance ratings

Chart 4 – Importance of performing functions

Chart: "How important is it for NEoLCIN to perform the following functions?" — a bar chart with a y-axis from 0% to 80% (gridlines at 0%, 20%, 40%, 60%, 80%) and x-axis categories: Very important (~68%), Important (~24%), Not very important (~2%), Not important (~0%), Don't know (~5%). Legend: Average importance ratings across all seven functions.
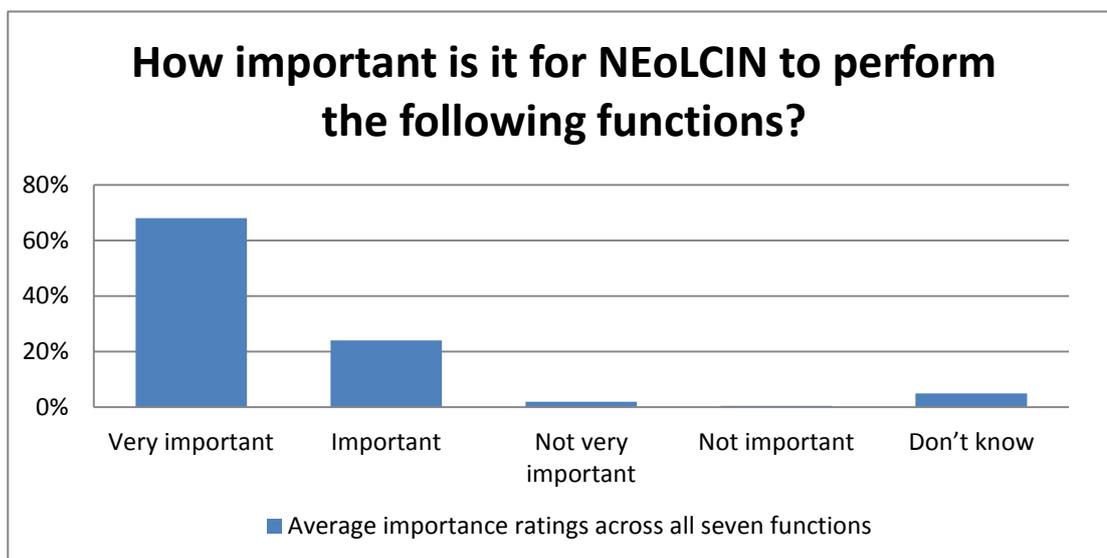
Table 2 – How important is it for NEoLCIN to perform the following functions?

	Very Important	Important	Not very important	Not important	Don't know	Response Total
Provision of data and intelligence to support quality improvement	74.61% (191)	20.31% (52)	0.39% (1)	0% (0)	4.69% (12)	**256**
Provision of data and intelligence to support best use of resources	69.14% (177)	25.78% (66)	0.39% (1)	0% (0)	4.69% (12)	**256**
Sharing of best practice	61.96% (158)	28.24% (72)	3.14% (8)	1.18% (3)	5.49% (14)	**255**
Provision of evidence to guide delivery of care	66.15% (170)	25.68% (66)	1.95% (5)	0.78% (2)	5.45% (14)	**257**
Working with partners to develop best practice in end of life	59.77% (153)	26.95% (69)	5.86% (15)	1.56% (4)	5.86% (15)	**256**
Support stakeholders to make best use of the data and intelligence available	67.74% (168)	26.21% (65)	1.61% (4)	0% (0)	4.44% (11)	**248**
Work towards improved national data about end of life care	79.28% (199)	16.33% (41)	0.4% (1)	0% (0)	3.98% (10)	**251**

Chart 5 – Individual functions importance ratings

% rating function as important/very important

NEoLCIN Function 1 to 7

(Bar chart values: 1 = 95, 2 = 95, 3 = 90, 4 = 92, 5 = 87, 6 = 94, 7 = 96)
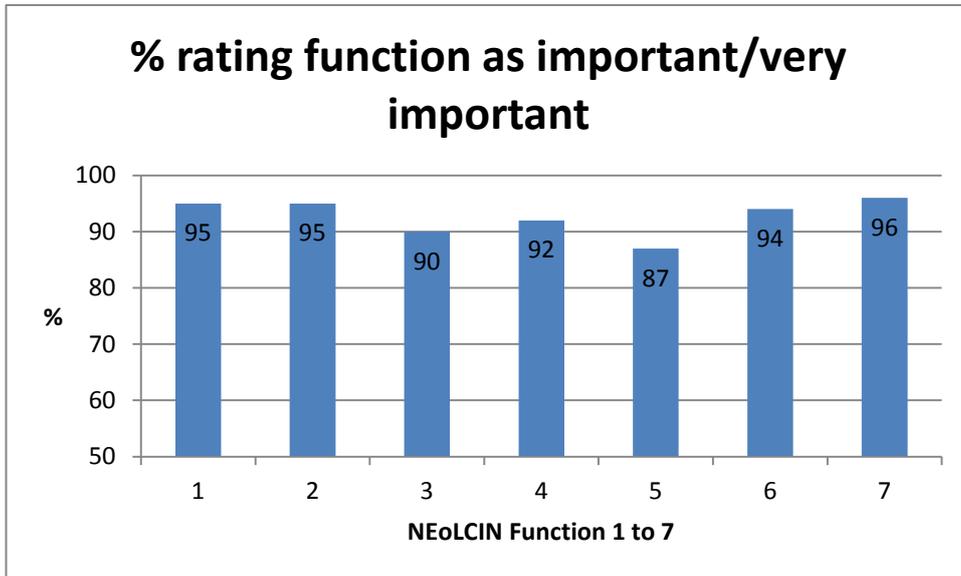
c)   Describing the NEoLCIN

The survey listed descriptions to reflect how people talk about the network. A majority of 60% said they would speak highly of the network. A third responded that they would be neutral if asked to comment on the network. Only six people out of the 255 who completed this question said they would be critical with or without being asked. Chart 6 shows the breakdown of responses. Note: the value of 0% against 'be critical without being asked' represents one response.

Chart 6 – Describing the NEoLCIN

When talking about NEoLCIN which of these phrases best describes what you would say? I would:

(Pie chart values: 19% Speak highly without being asked; 41% Speak highly when asked; 33% Be neutral; 2% Be critical if asked; 0% Be critical without being asked; 5% Not applicable. n = 255)

Legend:
- Speak highly without being asked
- Speak highly when asked
- Be neutral
- Be critical if asked
- Be critical without being asked
- Not applicable

d)   Impact

The survey asked people to rate the impact the network has made since being commissioned in 2010. Four categories were available for rating, the impact on end of life care generally, within a person's organisation, on their work, as well as within research and providing evidence. Chart 7 shows the responses. Over 50% rated the network as having a positive impact across all categories, and only five out of an average of 253 people responded that it had made a negative impact. A significant minority responded 'don't know'.

Chart 7 – Impact
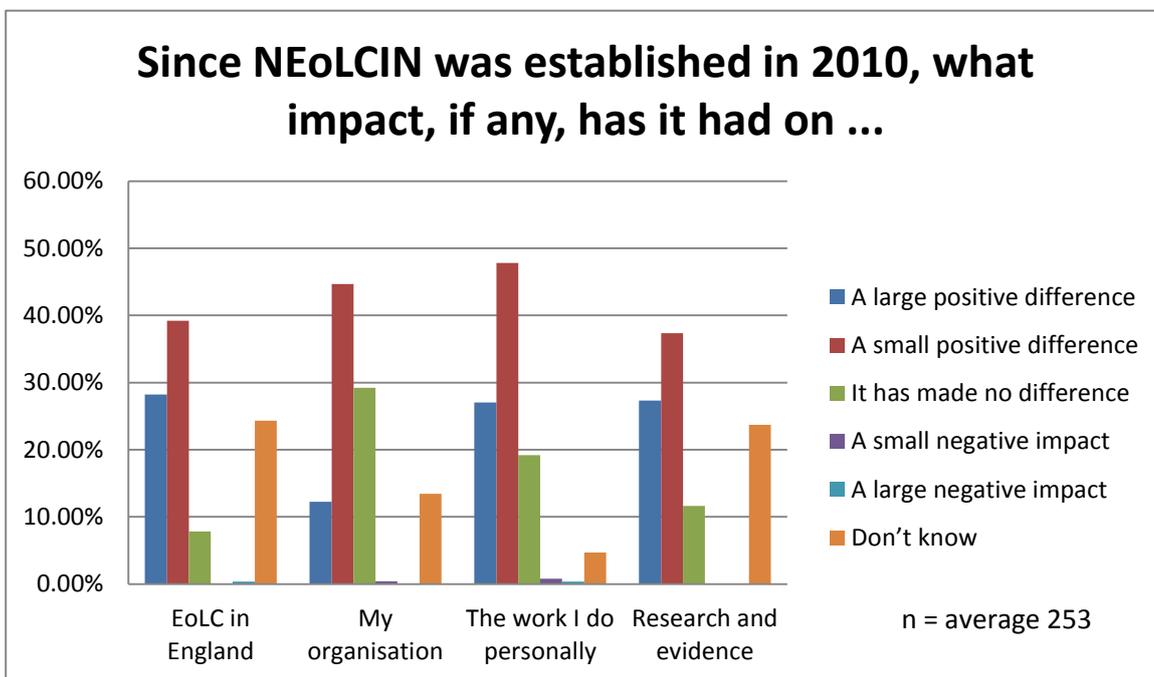
e)   Website usage

Section 6 contains more in depth detail on the analysis of usage of the website. However the online survey also included three questions relating to the website. The questions asked when people had last visited the website, what the reason was for the visit and if they found what they were looking for during their visit. Charts 8, 9 and 10 provide the breakdown of responses.

51% of the 243 people who responded said they had visited the site within the last week or month. 13% said they could not remember or had never visited the site. The reasons for visiting the site was quite evenly spread over four main areas – finding information they were aware of, checking for new information or updates, using end of life care profiles and accessing end of life care data/information. 76% said they had found what they were looking for on the site.

Chart 8 – Visiting the website

When was the last time that you visited the NEoLCIN website?

- Last week
- Within the last month
- 2 - 6 months ago
- Over 6 months
- Can't remember/Never

12%
39%
26%
10%
13%

n = 243

Chart 9 – Reason for visit

What was the reason that you visit the website? (select all that apply)

- Triggered by e-elert
- To find publication/information that you were aware of
- To check for updates/new information about eolc
- To use the eolc profiles
- To use the compendium/other data sources
- To access eolc data/information

21%
31%
34%
28%
6%
32%
8%

n = 271

Chart 10 – Finding data and information

Did you find what you were looking for on the website?

- 17%
- 7%
- 76%

■ Yes
■ No
■ Don't know/not applicable
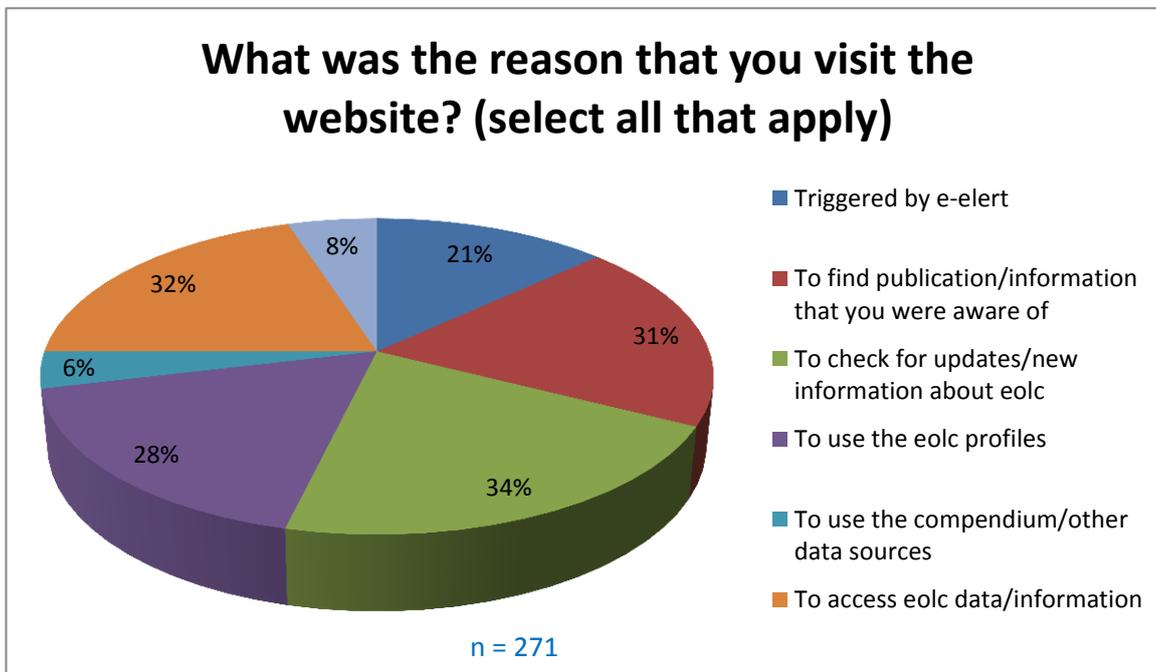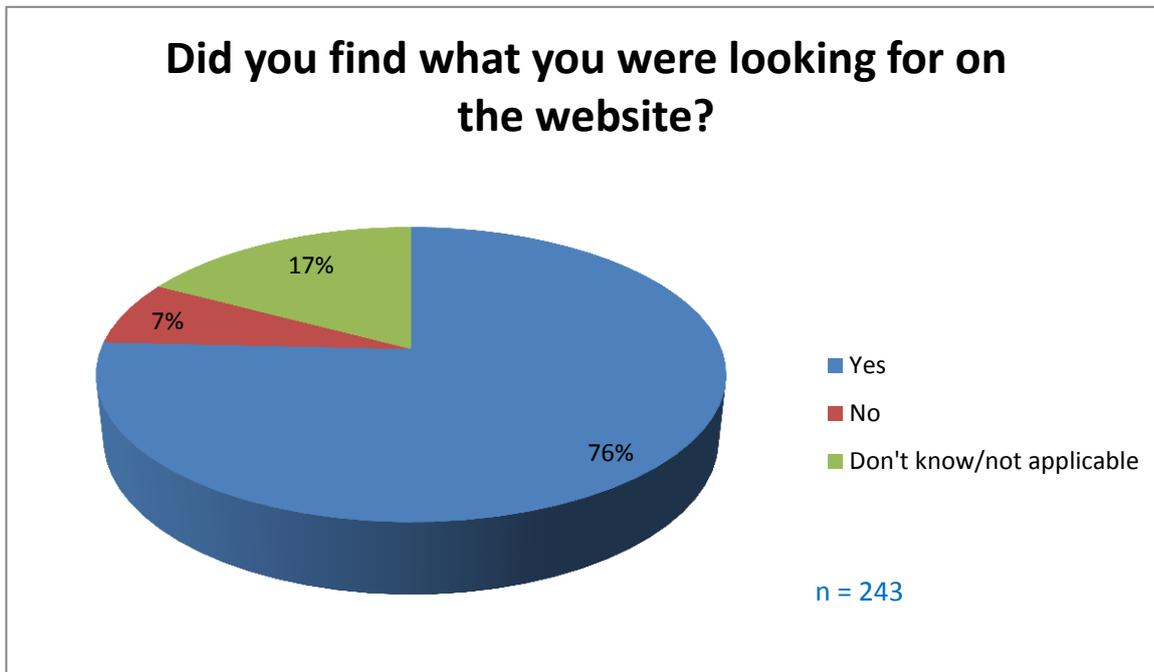
n = 243

f)   Usefulness and confidence in resources

Three questions on the survey focussed on how useful the resources are and the confidence levels people have when using them to improve end of life care.

Chart 11 and Table 3 show the responses to the question covering the usefulness of seven of the networks resources. An average 234 people responded and 64% rated the resources as useful or very useful when looking across all the resources listed. A significant minority (average 28%) did not know or had not used the resources listed, and nearly 18% rated ELCQuA as not very useful/not useful.
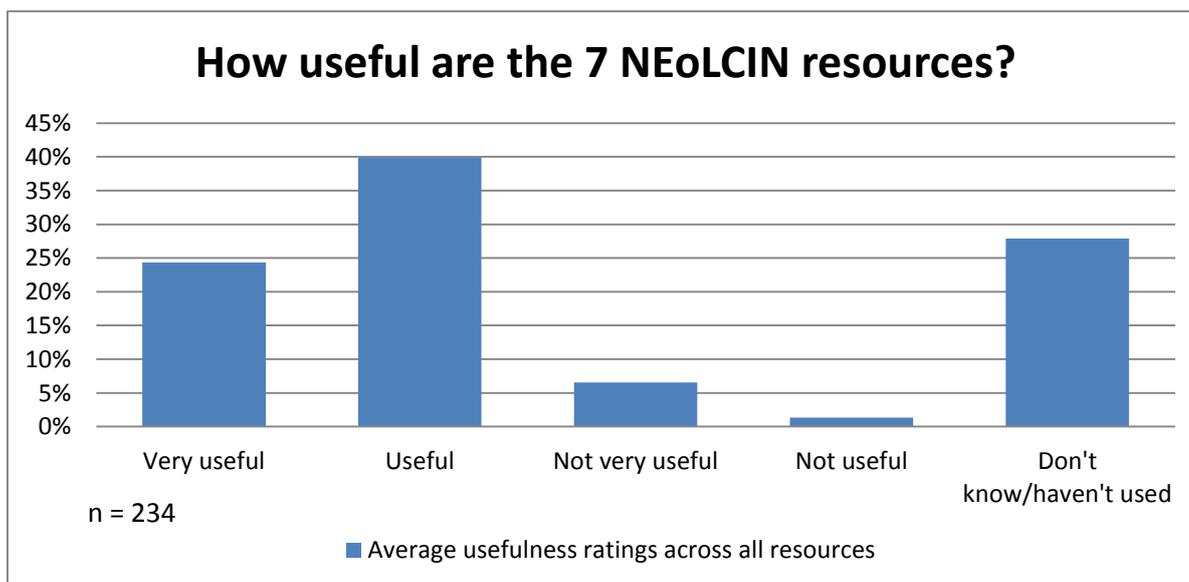
Chart 11 – How useful are the 7 key resources

Table 3 – How useful are the following NEoLCIN resources?

	Very useful	Useful	Not very useful	Not useful	Don't know/haven't used	Response Total
EoLC profiles	36.71% (87)	35.86% (85)	5.91% (14)	0.84% (2)	20.68% (49)	**237**
Compendium of data sources	16.46% (39)	46.84% (111)	5.49% (13)	0.42% (1)	30.8% (73)	**237**
ELCQuA	14.1% (32)	37.89% (86)	12.33% (28)	5.29% (12)	30.4% (69)	**227**
End of Life Care Modelling Tools	15.9% (38)	37.66% (90)	8.37% (20)	0.84% (2)	37.24% (89)	**239**
Publications	34.2% (79)	40.26% (93)	4.76% (11)	0.43% (1)	20.35% (47)	**231**
What we know now	35.02% (83)	35.02% (83)	5.06% (12)	0.84% (2)	24.05% (57)	**237**
National Information standard pages	17.95% (42)	45.73% (107)	3.85% (9)	0.85% (2)	31.62% (74)	**234**

Chart 12 also shows the individual resources ratings.

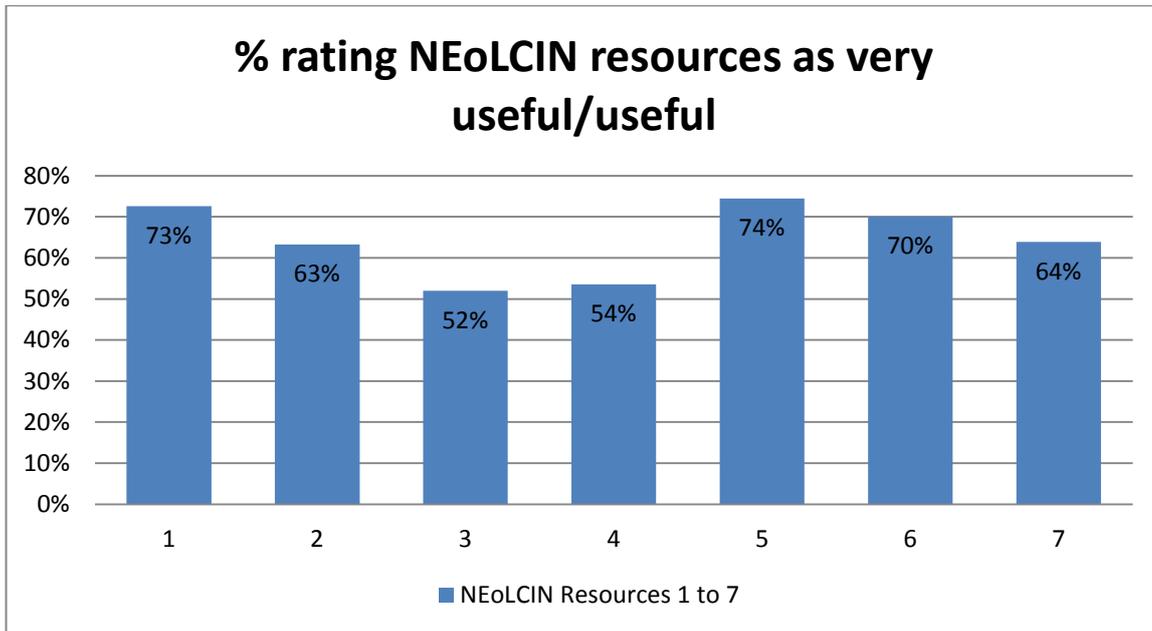**Chart 12 – Individual resources rated as very useful/useful**

Chart 13 shows the levels of confidence people have in using the network's resources to improve end of life care. 67% of the 243 people who responded said they were either very confident or fairly confident when using the resources. Only 10% were unsure and 14% were neither confident or unsure.

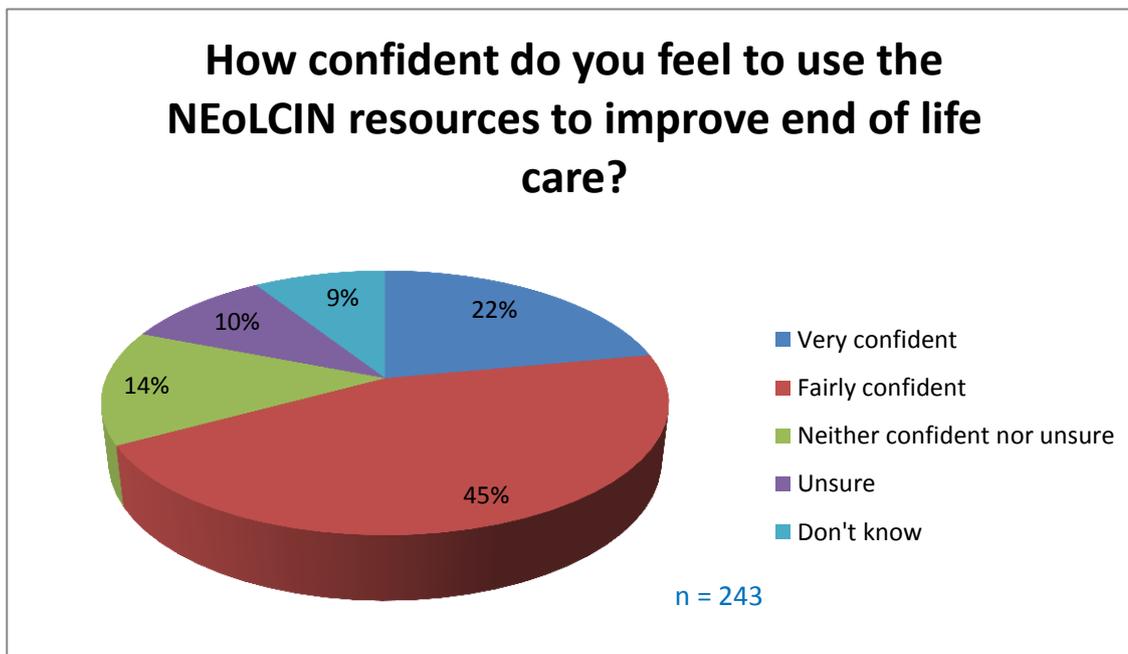**Chart 13 – Confidence in using resources**

Table 4 shows the response when people were asked to rate the resources against a list of criteria. The majority of people rated the resources as 'above average' or 'excellent' against all five criteria. An average of 70% of people of people rated the relevancy and usefulness as above average or excellent which was the highest rating (Chart 14). Although the timely provision of data had the highest percentage (8%) under 'below average' or 'poor', 55% of people still rated it as above average or excellent, however all ratings can be considered as good. A significant minority did respond as 'don't know' across all criteria.

Table 4 – How would you rate NEoLCIN resources against the following criteria

	Excellent	Above average	Average	Below average	Poor	Don't know	Response Total
Relevant and useful	29.46% (71)	40.66% (98)	13.69% (33)	2.07% (5)	0.83% (2)	13.28% (32)	**241**
Robust quality	25.63% (61)	42.44% (101)	15.55% (37)	0.84% (2)	0.84% (2)	14.71% (35)	**238**
Timely	16.67% (39)	38.46% (90)	21.79% (51)	5.98% (14)	1.71% (4)	15.38% (36)	**234**
Accessible	26.69% (63)	36.86% (87)	18.22% (43)	4.66% (11)	1.69% (4)	11.86% (28)	**236**
Easily understood	19.67% (47)	38.49% (92)	24.27% (58)	4.18% (10)	0.84% (2)	12.55% (30)	**239**

Chart 14 – Resources rated against criteria (above average and excellent ratings)
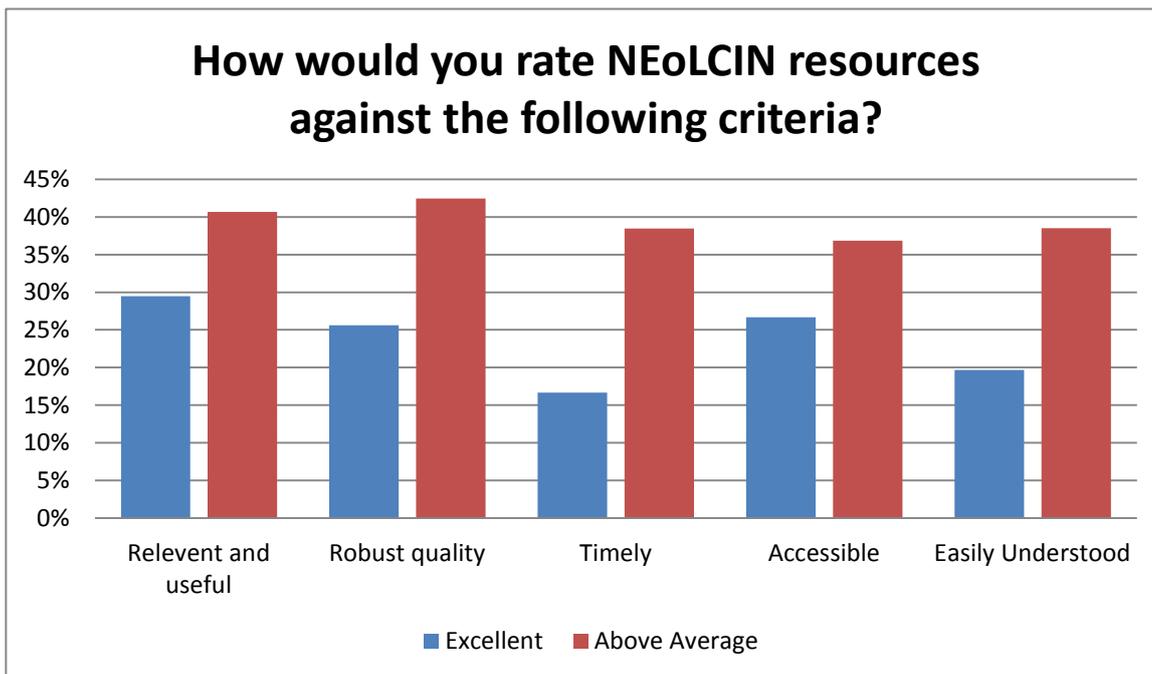
4.2 Online survey – free text analysis

Two questions invited free text responses:

1   What advice would you give NEoLCIN to help it improve over the coming year?
     (143 responses)

2   Please tell us what else you would like to see provided by the NEoLCIN and any
     suggestions for improving our publications and resources? (53 responses)

The following sections reflect the responses further broken down into themes and
include some of the actual comments received.

1   What advice would you give NEoLCIN to help it improve over the coming year?

Key results:

A very clear message to the network is that it needs to make sure it does not
duplicate the work of other organisations supporting end of life and palliative care for
example NCPC, Help the Hospices, Macmillan, Marie Curie and others.

The network was viewed as being well placed to influence national issues such
improving the links between data sets and integrated end of life care working across
sectors.

Raising the profile of the network, working closely with stakeholders and developing
more partnership working were common themes, improved engagement with GPs
and their practices were highlighted as a priority when undertaking raising awareness
activities.

Ensuring resources are aligned with developing care priorities, such as those
emergent from the Neuberger review, are important in supporting commissioners and
providers of end of life care services when undertaking service improvement
assessment and planning.

The responses would indicate high levels of interest in developing greater
involvement with the network especially at more localised levels and from
professionals working 'on the ground' and were reflective of the view that the network
should look beyond the usual stakeholders.

Comments reflected that people are looking to the network to continue to be a centre
of expertise and support around end of life care, and more help to support
development of local expertise in analysis and use of the resources was flagged up.

Reducing the complexity of data available across differing sources to enable those 'on the ground' to easily access the right data for their local needs was highlighted as an expanding role for the network.

Specific data items were highlighted, such as concerns around place of death as an indicator, and providing more context and narrative around data would support greater understanding of how best the data can be used.

Many mentioned the lack of more localised data reflecting the new organisational health and care infrastructure and timely up to date data as an issue, and believed that using data that is over one year old has little impact on assessing quality improvement initiatives.

Making the website more user friendly to access the resources and better communication of when the website content is updated or new resources added is needed.

Results by themes

Raising the profile

Raising the profile and working more closely with stakeholders and developing more partnership working were common themes. Suggestions included:

Widen the predominant focus on HES/ONS data.

Become more visible with more public relations, social media etc. explaining the role within the independent sector, social care as well as the NHS explaining the impact the network can make in supporting signposting, assessment and improvement plans.

Aim to be the first stop for end of life care information and ask users what data and information they actually want, and use their expertise (or ignorance) to tailor the approach.

Moving to PHE is an opportunity to re–launch the network and show what is on offer – road shows, twitter conversations/chats, become more accessible in localities so they know who to contact, study days/themed workshops.

Make sure all stakeholders and partnership linkages are maximised to ensure everyone is aware of all the useful information collectively available.

The following comments were made:

Whilst I am an active member of the local End of Life Board and am very aware of the activities of Dying Awareness, Cruse, Sue Ryder and the Leadership Alliance for the Care of Dying people, I was not aware of NEoLCIN so cannot be constructive in

responding. Suggest that the End of Life Boards in all districts are circulated with information.

To put in place opportunities to make the work of NEoLCIN more visible to stakeholders as well as the organisation itself. This is difficult especially as the organisation sits within PHE and people are still getting to grips about the new structures.

I was not aware of the network until now and will use it in my role. Data has been sent to me from this source, without me realising. I work in social care.

This is difficult to say as I'm not overly familiar with NEoLCIN, when I think of palliative care there are other organisations that would come to mind first. Perhaps making people more aware of their work and purpose.

Keep doing what you're doing, but perhaps more publicity and clarity is required.

Be even more vocal. You can never advertise or say too much!

Who are you?

Engagement

The responses would indicate high levels of interest in developing greater involvement with the network especially at more localised levels and from professional working 'on the ground', and were reflective of the need for the network to look beyond the usual stakeholders. Some of the suggestions on how engagement could be improved are included below:

Continue to develop two way communication like this survey with stakeholders.

Work openly with the voluntary and Carers UK type of organisations, they support unpaid carers and receive stories/information of what is not working in the hospital setting and people who would like to die at home.

Engage continuously with those of us on the ground and ensure that CCGs recognise the need for learning from the data and research evidence established. Don't give up as the sustainability will not happen and end of life care is now starting to be embedded into everyday practice.

More engagement with stakeholders and the professionals trying to secure funding for services and writing business cases. Statistical data is what commissioners respond to.

Find a way of engaging proactively with commissioners and providers of palliative and end of life care. The lack of wide publication of this survey speaks volumes, I

came to it through a link from the APM but I would have hoped to receive it from several sources.

An overview of the coming strategy and objectives for the year would help. Emails appear that can seem reactionary or too late for comment as work already complete. Appreciate it is difficult to have fully collaborative working with so many organisations but engaging/gauging their help at the beginning may be helpful.

Would appreciate regular opportunities to meet with counter-parts within the geographical region of our organisation, to enable a forum for stakeholders to discuss relevant pertinent matters, share best practice and support NEoLCIN in their endeavours.

I would like more opportunities to get involved.

Data: access and availability

Comments were received about specific data items, for example place of death within community hospitals and specialist palliative care units counted as acute hospital deaths and using place of death as an indicator, the network's team need to look into these in greater detail to establish whether it is misinterpretation of the data or if significant analytical gaps exist with the national data and the network can influence change. Many mentioned the lack of availability of more localised and up to date data as an issue as using outdated data has little impact on assessing quality improvement initiatives. Linked to this is the need to ensure data is broken down to reflect the new organisational infrastructure for example, CCGs, HWBs etc. To support people in using the data more effectively a number of suggestions were made about providing context around the data by providing accompanying narrative which can show how data may be used or as someone described it 'tell the story'. Comments included:

Perhaps clearer signposts to relevant data, sometimes can be confusing.

Continue to provide data for local areas for example CCGs the smaller geographical area the data can be provided for the better.

Be more systematic in the approach to research and evidence. Not just take evidence from small studies conducted by people well known to the NEoLCIN team. Be prepared to accept negative as well as positive evidence. Consider economics more rigorously. Try to get more nuanced database studies. Try to influence societal norms by consideration of cultural, ethical, and existential questions as these are central to issues of ill health, death and dying as well as bereavement.

Carry on as the data sources are great. Really like the end of life care profiles by CCG/PCT and Local authority as I can use depending on audience. Useful benchmark.

Develop evidence on how best local commissioners can capture preferred place of care data and quality outcomes across the health and care sectors and enable this to be measured and benchmarked nationally, because place of death as a key outcome measure is crude and a poor driver of quality improvement.

To continue to provide data to support individual trusts to benchmark services and outcomes. To continue to co-ordinate large scale service developments whilst providing support at provider level.

There is a need to understand data better, for example, death in usual place of residence if a person changes mind at last moment to die in hospital. It seems all hospital deaths are viewed as negative in data. It would be useful if possible to have a better reflection of why people ended up going to hospital to die (this data is very difficult to find though).

Improve research outputs and links. Occasionally the information and reports restate what is already known in the research field but promote themselves as finding things out for the first time. It might be good to develop a more robust approach on each.

Keep publishing data. Also information on how data has been used, practical examples of best practice, education and training around end of life care. Also future trends identified by data.

It should concentrate on giving local teams information that supports their activity. In my area getting information from the EPaCCS to inform progress on local trust based initiatives is well-nigh impossible.

Keep going! Our best chance of local and comparative data.

NEoLCIN role/scope/function

A number of strong themes emerged from the responses. Raising the profile, working in partnership both nationally and locally and being more visible came through as they had in other areas of comment. A very clear message was that the network needs to determine and make sure it does not duplicate the work of other organisations supporting end of life and palliative care for example, NCPC, Help the Hospices, Macmillan, Marie Curie and others.

From the comments made it would confirm that the people are looking to the network to continue to be a centre of expertise and support around end of life care by providing evidence based quality data and information, but to also provide more support in showing how the data can be used to improve services. Reducing the complexity of data available across differing sources to enable those 'on the ground' to easily access the right data for their local needs, and supporting development of analytical and

practical application through tools, workshops and case studies were highlighted as an expanding role for the network.

> The only data set I engage with is the MDS. I'm really sorry, this is the first contact I've had from you and I've been in post for 12 months. I'd like to know what you are doing though I'm an enthusiast; just not sure your message has reached me!

> Decide how your role differs from the National Council for Palliative Care, Help the Hospices, Together for Short Lives, the EoLC Leadership Alliance, the Association for Palliative Medicine, the Association for Paediatric Palliative Medicine, Macmillan and Marie Curie. Your strength is in national data collection. Do not duplicate what already exists.

> I would like it to extend its role and include children and young people in its remit.

> You need to provide technical leadership. It is currently non-existent and must be costing the NHS millions.

> To keep in touch with 'on the ground' practitioners. To encourage standardisation of end of life tools for better co-ordination.

> The organisation of end of life care requires leadership and vision, supported by excellent data where available and by data collection that meets the needs of those organisations who are planning services. Possessing data and not using it for the public good is inexcusable.

> Support of NEoLCIN to highlight examples of best practice, and to support exploration of new ways of working, would be fabulous. Get out there and make the service you offer visible, accountable and accessible to people who work to deliver end of life care, and not just to data managers in large, non-clinical organisations.

> More focus on inequalities, be more engaged in work across PHE and integrated in its approach. Be less of an island/ivory tower.

> Look at ways of integrating their work with other national and local work streams. One of my biggest frustrations is that there are so many separate work streams, groups etc. that don't seem to be working together. I wonder if some sort of national mapping exercise would be useful?

> More focus on skills development in relation to analytics and business information within the sector. More focus on supporting practical application of available data through tools, workshops and case studies etc.

> Increase work on sharing best practice and research.

Resources

Making the website more user friendly to access the resources was highlighted and better communication of when the website content is updated or new resources added was mentioned. Ensuring that resources are aligned with developing care priorities, such as those from the Neuberger review, was seen as important to support service improvement assessment and planning. Signposting to all evidence and resources available from wider health and social care sources known to support best practice in end of life care is seen as valuable if undertaken by the network. Comments made were:

Having been involved with ELCQuA it did take a number of professionals quite a number of hours to actually understand the tool and how to use it before it could then be used to gather the baseline quality assessment information.

I have struggled to use the website, really need to sit down for a couple of hours and get to grips with it. Please make as user friendly as possible.

Continue to use all the evidence and resources available, not just NHS resources but those known to be useful that centre on best practice. It is critical that end of life care programmes, see end user consultation and inclusion as vital to gaining some of the best improvements.

Try to support palliative care as a whole to engage with the government driven Open Data programme and seek out how this may further support provision of palliative and end of life care.

Other

A significant number of comments were received suggesting that improved engagement with GPs and their practices should be a priority when undertaking raising awareness activities. Continued support for the network was evident with many suggestions around how it could improve how it works, which are repeated from other themes, but also it was considered well placed to influence national issues such improving the links between data sets and partnership working to support integrated end of life care across sectors. Comments received included:

A greater impact on GP surgeries, many still do not know enough about it to support care homes, which will in effect reduce hospital admission. People are not aware of what is out there, and that they can access end of life is not just for people which suffer from Cancer, a big chunk is people with dementia, heart failure etc.

1. It is very health care focussed when information should be taken into account from social care. 2. I read reports on the website which gives useful information but then

there are no recommendations or outcomes or what happens next. 3. Use more plain English, less jargon.

Drive forward electronic end of life care register, influence government to address the interoperability between different software systems as this is a major barrier to sharing information and inhibits integrated collaborative working.

To continue: as supporting good quality end of life care is essential. Better links into social care, look at what multi agency working/developments are there and how can this link be developed for the better.

Ensure that all parties involved in end of life care are talking to each other so that the right hand knows what the left hand is doing.

Continue to make organisations aware of the work that you do and the benefits aimed to drive up quality standards in end of life care. Thank you.

Extend to all of UK.

Stick with it and get info out to all as much as possible!

2   Please tell us what else you would like to see provided by the NEoLCIN and any suggestions for improving our publications and resources?

Key results:

People want to ensure they are kept informed about what is offered by the network and how the network will support emerging care priorities and guidance.

Improved availability and flexibility of up to date data sets that can be easily integrated across sectors and settings for usage to reflect local priorities was a main theme.

Help in interpreting research evidence and data, improvements to the website and more advanced search criteria are suggested.

More information needs to be available on interventions or commissioning activities that have produced positive results within the UK and nationally.

The network has a role in resolving incompatibility issues of data sets across various systems and resources, and could provide a level of technical leadership.

There were a number of comments on ELCQuA highlighting problems, these need to be considered further as part of the evaluation of ELCQuA planned for summer 2014.

Comments by themes

Supporting stakeholders

From the relatively small number of responses it can be seen that people want to ensure they are kept informed about what is offered by the network and how the network will support emerging care priorities and guidance. Providing greater understanding when research evidence is available on how it is interpreted rather than just providing data was again highlighted. Comments received included:

> An annual central register reminder of all that is available sent as an email rather than having to go and find this out from the website.

> Rigorous research evidence as well as data crunching, so understanding of which evidence is strongest, a grading of evidence. End of life care to be culture driven rather than document driven.

> Support with a standard way to commission end of life services and to define the currency in line also with the Palliative Care Funding Review.

> Support with a standard way to commission end of life services and to define the currency in line also with the Palliative Care Funding Review.

Suggestions for new resources

Improved availability and flexibility of up to date data sets that can be easily integrated across sectors and settings for usage to reflect local priorities was a main theme, and improvements in the website and more advanced search criteria are suggested if this is to become a reality. More information needs to be available on interventions or commissioning activities that have produced positive results within the UK and nationally were flagged. People believe the network has a role in resolving incompatibility issues of data sets across various systems and resources and could provide a level of technical leadership.

Provision of seminars, possibly online, and resources and publications responding to care sector needs as well as from the service user perspective were also mentioned. Some of the suggestions are probably more appropriate for the networks partners to produce with the networks role limited to signposting where to get help.

Related comments included:

> Evidence regarding what commissioning activity produces best results would be helpful.

I know that this is affected by what data are available, but more up to date info would be useful for local benchmarking etc.

More international data or how best practices could be transferred to other jurisdictions. I work on end of life are in Ontario, Canada.

Develop evidence on how best local commissioners can capture preferred place of care data and quality outcomes across the health and care sectors and enable this to be measured and benchmarked nationally, because place of death as a key outcome measure is crude and a poor driver of quality improvement.

Create standard templates for use in all clinical systems. Resolve the issue that disparate clinical systems cannot inter communicate. Find cost effective answers to these that we can all use, rather than every CCG reinventing the wheel itself as now.

My work is to support care homes with end of life care so any publications that can be relevant to this group will be useful. There is a lack of resources re verification of expected death, which the care homes find problematical.

Greater capacity to interrogate information about hospital deaths for example, what is the mean time to death for those that die in less than seven days.

Comments on existing resources

There were a number of comments on ELCQuA highlighting problems, these need to be considered further as part of the evaluation of ELCQuA planned for summer 2014 and not discussed further within this report.

A number of people reflected that until the survey they had not been aware of the range of resources currently available. Issues around the availability of up to date data and the user friendliness of the website were raised again.

Comments included:

Having filled in the survey I am obviously not aware of all the resources there are, either this needs to be publicised better or I need to go and have a good root around!

Local data, CCG level. National reports, although interesting, cannot really influence what we do locally.

I generally use the profiles and not the other resources, however I will start to use the other sections more frequently more now.

User friendly guides, not all publications are easy to interpret.

The recent standards and electronic resource publications were woeful and the LACDP initial response was very wordy and too watered down from the discussions at which I was present.

My apologies, but in the 6+ years I have been involved in cancer research and since my own end of life diagnosis (with a stay in a hospice), I cannot recall knowing of you or your activities. Maybe the many who helped me were so informed and so formed the basis of their assistance; but I did not. I may have obliquely heard of you at the many NCIN meetings I have attended, but that's it.

Regular updates of the info already produced and more extensive info in future please.

In some cases they need to be made more user friendly with headlines that lead to specific points/findings.

Service redesign requires current data to understand what is currently happening. I find the intelligence network a great resource, particularly when the voluntary sector find it hard to source this kind of data.

Hospital profiles. More up to date information. Data from 2012 is only useful to compare to previous data it is not current enough to be useful going forward. Data developed on CCG footprint.

Other

Most of the comments have already been picked up under previous themes, but most related to a lack of awareness of the network and the resources it can offer. Comments that reflect this include:

Would like to have known about the resource before.

I clearly need to explore the website.

We don't know as we haven't investigated your resources however will do now. My nurses are on the website already.

Are you authorised by The Care Quality Commission? Are you a government body? Why have you not mentioned The Care Quality Commission anywhere?

Hot press publications by email sign up.

4.3   Online survey – profile of online respondents

People completing the survey were asked to provide information about them, including the nature of their work/involvement, their name, email address, job title and their organisation. For the purposes of this evaluation report to maintain the information relating to the nature of their work/involvement (Chart 15) has been considered as relevant, and other data can be used by the network team if issues have been raised that need a priority response.

52% of those the 237 people who provided this information about themselves came from the NHS with the voluntary sector coming second highest with 20%. Only 7% (17) came from social care.

Chart 15 – Nature of work/involvement
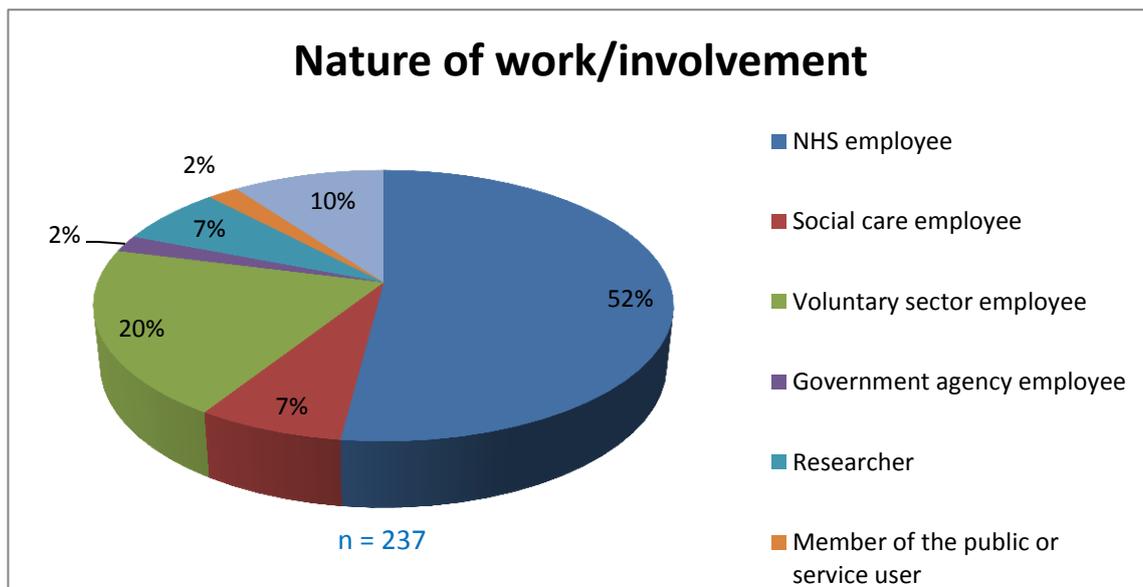
5 Evaluation results – stakeholder interviews

A wealth of feedback was obtained from the stakeholders and needs exploring in further detail through the wider stakeholder group as well as the NEoLCIN executive team, to inform business planning for the next three to five years.

Overall the network is well thought of and supported and all of those taking part in the interviews believed data and information provided by the network had made a difference. The stakeholders provided constructive comments underpinning their commitment to enable the network to go from strength to strength and to secure its future. The network was commonly described by the stakeholders as' being a resource to gather intelligence, rather than undertaking traditional research, and support service improvement by enabling assessment and signposting through the availability of end of life care data in a manageable format presented in a number of different ways, for example, geographical, disease specific and by care setting'. The following reflect the common themes that emerged during the discussions.

5.1 Summary of emerging themes

a)   Raising awareness

Those that know about the network value its contribution, but more work needs to be undertaken to become better known and to raise awareness of what the network can offer. To widen the usage of the network and help health and social care organisations and professionals across sectors understand what the network can offer (answering the 'so what' question), a number of suggestions were put forward:

Establishing strong partnerships and data sharing across sectors will assist in promoting the network into new areas, for example, the end of life care hospitals programme (Transform) has raised awareness and provides information to the network of acute trusts involved, Help the Hospices has signposted the data to support local hospices plan service developments and APM raised awareness of the data to inform its commissioning guidance.

More needs to be done to show organisations and professionals how they can engage with the network and how the data and information can be used – answer the 'so what' question with practical and localised examples to address the theory/practice gap, tell the story!

Provide examples of how the network can respond and support implementation of recent review recommendations such as the Neuberger review, the new regulatory CQC inspection regimes, the forthcoming 'Ambitions for end of life care' NHS England review, and new service improvement developments such as integrated working pioneers and House of Care modelling.

Consider local workshops for jobbing clinicians and other professionals in specialist or generalist practice. The reality of bringing together local CCGs, HWBs and LAs to a specific workshop is limited, so look to integrate raising awareness sessions within other localised learning events and workshops.

Provide regular updates within partner organisations bulletins to reach wider networks, use stands at conferences and other available media to raise awareness.

To engage those on the periphery or generalists who are looking for further related information for example, comorbidity data, integrated care, health and social care trends etc., the network must be easily 'googled', be easy to find and be visible!

The website and other communications must draw in individuals seeking information by presenting data in a more responsive way by focussing on the needs of potential new users. It should also contain a narrative/video explaining up front how to apply the resources and data locally, again responding to the 'so what' question.

The website must use up to date terminology for example references to data broken down by PCTs will be off putting to many and it should be more reflective of cross sector data and information being available.

These suggestions need to be further reviewed with the results from the online survey.

Confidence and timeliness of data – The feedback reflected four main areas:

1. Generally confidence was fairly high with the underpinning work by the South West Public Health Observatory (now part of PHE) being cited as the main factor due to its reputation for reliable and accurate use of data, which gives authority and validity to the work the network produces.

2. The data is as reliable and complete as the data will allow – there are holes in the data which need to be acknowledged and the network needs to say how and when it can be improved, for example more localised data aimed at HWBs, CCGs and LAs.

3. Issues around timeliness of the data and the need for it to be more up to date were the most common themes.

4. Problems arise when trying to cross reference data with comparable data sets from other sources – combining and linking related data sets were seen by a majority as a priority.

It was suggested that issues around spending time validating and challenging data when the degree of accuracy is not relevant for its usage, at the cost of providing more up to date data sets, needs to be reviewed if support for strategic planning is to be a priority. A quote from John Kenneth Galbraith reflects some of the tensions when trying to achieve a balance:

'Faced with the choice between changing one's mind and proving that there is no need to do so, almost everyone gets busy on the proof.'

b)   Partnership working

The role of partnership working with other organisations across all sectors holding end of life care related intelligence was seen as very important for improving the provision of comparable, reliable data sets and avoiding duplication. This did not imply that all data should be held by NEoLCIN, but it could be signposted to giving improved usage and accessibility to existing and new users.

c)   Role and focus

The network should be clear about its focus, target audience and the unique role it aims to fulfil. Suggestions included:

- providing measures to enable strategic planning judgements and assessment at national and local level (CCGs, HWBs, LAs and professional staff across disease specific and generalist areas) to be made through signalling and signposting
- supporting new inspection regimes by working with CQC
- identifying new research questions and forming partnerships to develop measures for comparative research
- reviewing data capture, timeliness and range of end of life care data by working with partners to scope opportunities for combining/linking data sets to improve accessibility and quality
- providing a platform for resources to support planned quality improvements and answering the 'so what' question through practical examples and showing how the resources support service improvement planning across sectors

d)   Stakeholder group and resources

The external stakeholder group's membership must be appropriate to steer and advise the future work plan needed to extend usage into areas identified and reach a wider audience. PHE must ensure the network is resourced to enable it to deliver a well-regarded, high quality service to support improvements in end of life care across sectors.

6 Evaluation results – website usage

Information on use of the website has been collected for four years (Tables 5 and 6). Information on popular publications and downloads are included.

Results from the online survey indicated that 76% of people who responded could find what they wanted on the website. Overall the 'What we know now' series of reports were the most popular download.

A detailed breakdown can be found in Appendix 1 Tables 7 to 10.

Table 5 – Visits in first four years

	Year 1	Year 2	Year 3	Year 4
Visits	21,285	27,272	45,138	40,034
Unique Visitors	12,239	17,600	29,769	27,743
Page Views	76,905	105,278	191,897	143,930
Pages / Visit	3.61	3.86	4.25	3.60
Avg Visit Duration	3:44	3:58	3:43	3.11
% New Visits	57.40%	60.98%	61.93%	66.12%

Year 1 – 1 May 2010 – 30 April 2011
Year 2 – 1 May 2011 – 30 April 2012
Year 3 – 1 May 2012 – 30 April 2013
Year 4 – 1 May 2013 – 30 April 2014

Table 6 – Top three resources by Year

Year 1	Year 2
Variations in place of death in England	Deaths from Liver disease: Implications for end of life care in England
Predicting Death: Estimating the proportion of deaths that are 'unexpected'	Deprivation and Death: Variation in place and cause of death
Deaths in Older Adults in England	Variations in place of death in England

Year 3	Year 4
What do we know now that we didn't know a year ago? New intelligence on end of life care in England (2012)	What we know now 2013: New information collected by the National End of Life Care Intelligence Network
Deaths from Liver disease: Implications for end of life care in England	National Survey of Patient Activity Data for Specialist Palliative Care Services (2011-2012)
Deaths from Cardiovascular diseases: Implications for end of life care in England	End of Life Care Co-ordination Implementation Guidance

7 Conclusions

Overall between 250 and 300 people took part in the evaluation and the majority of responses across all areas should be interpreted as positive, with only a small minority giving negative feedback. However, a significant minority of responses reflected that people either did not know enough to form an opinion or had not used the resources. It was evident that a number of themes recurred across both survey methodology, which would suggest that the sample size was sufficient for the evaluation to be reliable.

It is suggested that the network's team review the comments made in the free text element of the online survey and within the qualitative interviews in more detail, especially those that were data item specific or highlighted an issue of access that could easily be resolved. A number of negative comments were made about ELCQuA, which should inform the separate evaluation of ELCQuA being undertaken.

It is clear that many of its current partners, and those who use the data, information and tools to inform their work value the network and its team. The results would imply that overall what is provided is to a high standard, and has made an impact on end of life care services since being commissioned in 2010. However the network needs to review whether this is still appropriate for attracting a wider audience, as well as what may need to be discontinued to enable new resources linked to care priorities to be developed.

Suggestions made within the evaluation are aimed at supporting the network to secure its place as a national expert resource to inform and support improvements in end of life care across all sectors. The challenge for the network and PHE is likely to be managing the expectations of those who have suggested an expanded role for the network, and the feasibility and options for delivery within finite resources, both financially and the availability of data.

It was acknowledged that the past twelve months have been a transitional year when hosting arrangements changed and many suggested that it would be timely for a re-launch.

The common themes that should be considered by the executive team when planning future priorities are:

- the network must be clear on its role and function, raise awareness by communicating this more widely across sectors, keeping people informed and not duplicate the role of other end of life care focussed organisations

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- it should build on the goodwill it has garnered and extend partnership working, as a clear willingness exists to work with the network from organisations and individuals. Each partner's role must be clearly understood, and signposting to information and resources held by partners needs to be well defined

- whilst a significant number of people expressed a need for more localised data and widening the scope, the network must be realistic about its ability to meet that need. For data to be usable at local level, it must be up to date and produced at frequent intervals, or be available for interrogation on the website

- to meet the network's aim of supporting NHS England, CCGs, HWBs and LAs to make strategic planning judgements and assessments at national and local level, the data has to be up to date. Validating and challenging data reliability against the degree of accuracy required for its usage needs to be explored further if these new bodies are to remain the target audience

- with the backing of PHE as a credible and nationally recognised organisation, and engagement with the research community, the network is well placed to become more widely acknowledged as a reliable centre of expertise across sectors. It should aim to influence change, fill gaps and resolve incompatibility in data sets collected nationally by other agencies relating to end of life care, as well as identifying new research questions

- the network needs to respond to the 'so what' question if it is to extend its usage. Providing more narrative about how data, information and resources can be used with clear examples and reducing complexity of presentation, as well as skills workshops on how to interrogate the data, and make best use of the resources should be considered

- the website and communications generally need to be reviewed and updated in light of the comments received. Effort and resources should be focussed on those publication, tools and resources shown as being most viewed or downloaded. New resources and tools should be developed as direct requirements of the target audience

Appendix 1 – Detailed website usage

The following tables provide a breakdown of website usage.

Table 7 – Visits during the year 2013/14

	Q1	Q2	Q3	Q4
Visits	10,003	7,492	10,107	10,922
Unique Visitors	7,103	5,440	7,375	8,277
Page Views	38,489	28,147	35,952	37,143
Pages/Visit	3.85	3.76	3.56	3.40
Avg Visit Duration	3:20	2:52	3:38	2:52

For 2013/14 the % of new visits is 66.12%, which is an increase on the first three years (Table 5).

Table 8 – Downloads of recent publications in 2013/14

Publication Name	Downloaded
What we know now 2013: New information collected by the National End of Life Care Intelligence Network	2098
National Survey of Patient Activity Data for Specialist Palliative Care Services (2011-2012)	1213
End of Life Care Co-ordination Implementation Guidance	515
Deaths from Liver disease: Implications for end of life care in England	509
What do we know now that we didn't know a year ago? New intelligence on end of life care in England (2012)	506
Deaths from Cardiovascular diseases: Implications for end of life care in England	411
Variation in Place of Death in England	385
End of Life Care Co-ordination Record Keeping Guidance	361
Deprivation and Death: Variation in place and cause of death	280
Classification of place of death: A technical bulletin	160
Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK	127
End of Life Care Co-ordination Summary Record Keeping	126
Deaths from Urological Cancers in England, 2001-10	103
Understanding Patterns of health and social care at the end of life	98

Table 9 – Website pages accessed in 2013/14

Website Pages	Accessed
End of Life Care Profiles	30448
Resources page	21762
Home page	14467
Compendium of Data Sources	12994
EoLC Modelling Tools	5677
News page	3960
Advice and Information	1757
National Information Standard pages	3577
About the National End of Life Care Intelligence Network	866
Events page	613

Table 10 – NEoLCIN web tools downloaded in 2013/14

Popular Web Tools	Accessed
Proportion of deaths in usual place of residence	1131
End of Life Care Core Content (link to ISB pages)	680
End of Life Care Local Authority Profile Instant Atlas Tool	621
End of Life Care Local Authority Profiles - Indicators Metadata Guide	590
End of Life Care Primary Care Trust Profiles	441
Variations in Place of Death in England	387
National Bereavement Survey (VOICES)	157