Outline script for webinar Atlas of Palliative and End of Life Care given 10th December 2018

Slide 2. Good morning. I'm Andy Pring and I work as an analyst in PHE for the National End of Life Care Intelligence Network. I'm going to speak to you for about 15 minutes about the recently published Atlas.

Slide 3. I'm going to give you all a little background to the Atlas, and its context in a series of atlases of variation. I will describe to you what the EOLC Atlas contains and bring to your attention just a few of the specific indictors and what they show. I'll mention the resources that support the Atlas and together with Nicky will answer any questions that you ask.

Slide 4. The first atlas was published in 2010 and there have been a series of them since then. They have the common aim of better understanding the variations in healthcare outcomes, healthcare activity and service configuration across the country. The source of variation can be; 1) **random**; 2) **warranted -** reflecting factors such as patient preferences, innovation in person-centred care and clinical responsiveness, that is - local needs and priorities shape services. 3) **Unwarranted** - defined as variation in the way care is provided that cannot be explained by differences in patient illness or patient preferences and offers no improvement in outcomes.

Slide 5. You are probably aware that the atlases are published on the Fingertips website. I've listed here the previous publications.

Slide 6 and now ours

Slide 7. The palliative and end of life care atlas follows the pattern set by earlier atlases, the main pdf document includes a scene setting Introduction, a background to the data guiding readers how to interpret the maps and charts, the main body which comprises presentations of 27 indicators and an extensive set of references. Where we could, the indicators are produced by CCG, the others are by local authority, or because of the need to obscure small numbers, and one indicator is published at STP level.

Slide 8. For each specific indicator there is a two page summary presentations. This is an example of the first page, 2 maps which I will describe in more detail a little later.

Slide 9. And this is the second page, boxplot trends and column chart depiction of variation both across the country and over time together with a brief discussion of the measure. Where we can we have included references to best practise guidance, academic literature and other resources. Again I will go through an example in just a moment.

Slide 10. We also publish an extensive meta-data document describing the data sources and methodology behind each indicator. A spreadsheet containing all the indicator data, a slide pack of the maps in the atlas and an Instant Atlas – this is published on the Right Care website. I'll show you what it looks like later on.

Slide 11. The **introduction** sets the scene and describes some of the national trends in key end of life care measures. It starts off by establishing that the demand for end of life care is increasing and changing. Slide 12. As part of their population projections ONS project forward the annual number of deaths –we see on this chart actual figures 1995-2016 and projections for 2017-2040 - they suggest that the number of deaths each year in England will rise considerably over the coming years

Slide 13. The nature of those deaths is changing. This chart shows the number of deaths each year 2006-2016 by age at death. Over recent years the deaths under 75 years have been stable year to year, but over 75, there has been a reduction in those aged 75 -84 and a rise in the number of deaths that are 85 years or older.

Slide 14. The pattern of cause of death is changing. This chart shows the trend in number of deaths between 2007 and 2016 by age and cause of death. Each sub-chart describes an age-band, each colour of line describes the cause of death. In case you're wondering this chart does not include all deaths, but focusses on a couple of leading often chronic causes that our steering group felt illustrated some of the patterns going on. For 2 of these conditions, Dementia and COPD we have presented figures for people with any mention of the condition on their death certificate. For the others we looked on in the underlying cause of death. Advances in healthcare have reduced the early deaths from circulatory diseases (the red and green lines). But with more deaths at older age, we see an increasing proportion of deaths with co-morbidities. Dementia is a particular issue, as good end of life care involves communication, choice and advanced decision making – all things that can be a challenge for some people living with dementia and having reduced mental capacity.

Slide 15. OK – let's leave the introduction and take a look at the indicators. There are 27 indicators which we have divided loosely into 3 sections –The need for EOLC, the role of hospitals, and the role of the community. I quickly take each in turn …

The **need for end of life care**. Slide 16. These indicators describe the age at death and projected number of deaths, census based socio- demographic indicators and descriptions of the proportion of deaths with particular causes of death. For most of the latter we describe underlying cause, but for 2 - dementia and COPD – we report the deaths with underlying or contributory cause.

Slide 17. As I mentioned, for each indicator we produced 2 maps, on the left a quintile map and to the right a significance map. Often they appear similar, but they are by definition different. These particular maps describe the proportion of deaths who are 75 years or older. Let's look at the quintile map first. There a couple of ways quintiles can be defined. In this atlas it was decided to define the range of each quintile by dividing the total range in the recorded values into 5 equal ranges – for example if the range from maximum to minimum was 10%, then each quintile would be 2% wide. Typically this means there is not an even spread of areas in each quintile. The other map, on the right, is a significance map – using the confidence interval around the area value to categorise it as significantly higher than England (either at 99.8 or 95%), not significantly different, or significantly lower than the England value. Taken together these maps shows that certain urban areas have a low proportion of deaths that are 75 or older, in particular parts of London, north west and north east. The quintile map legend gives you the maximum and minimum figures – ranging from just under 52% to nearly 78%. This legend also shows the number of CCGs in each quintile - 50, that is a quarter of CCGS are in that highest quintile of between 72.6% and 77.8%.

Slide 18. The **role of hospitals**. Slide 19. These indicators describe the proportion of deaths in hospital, a few indicators we developed using Hospital Episode Statistics, and 4 which are taken from a National Care of the Dying Audit of Hospitals. The indicator 3 or more emergency admissions in the last 3 months has recently been adopted by NHS as an EOLC measure. Arguably the audit measures are the only direct measure of quality of care we have in the atlas – the acknowledgement the end of life may be near, communication to the individual and relatives and a more holistic needs assessment which includes the spiritual needs of people a really important indicators of good care. The 4th audit measure is the yes/no measure, whether or not the trust provides face-to-face access to specialist palliative care services at least 9am-5pm 7 days a week.

Slide 20. One of the clearest observations about EOLC in recent years has been the steady reduction in the proportion of deaths in hospital. This is the **box plot** for that measure. It describes the trend in the variation in the proportion seen across CCGs - each individual boxplot has an inner coloured block which describes the inter-quartile range – where the middle 50% of CCGs lie – the centre line represents the median value (which is not the same as the indicator value for England). The whiskers extend up and down and show the range of values seen across all CCGS. The intermediate ticks indicate the 5th and 95th quartiles – i.e. for the 200 odd CCGs the range between the intermediate tick and the extreme indicates where the highest 10 and lowest 10 values lie and can be useful to identify outliers.

Slide 21. The maps for this indicator raise some questions about geographic variation with low hospital death rates in the west, south, and east of the country and high rates in London in particular.

Place of death has been used as a proxy measure of quality of end of life care. But it is now losing favour. It was used because surveys have suggested that most people when asked express a preference to die at home or in a hospice. Also, research has found that one of the outcomes of good end of life care including advance care planning is reduced hospital admissions and consequently fewer deaths in hospital. However, these reasons are not quite the same thing as saying that deaths at home are somehow "better", and there has been concern that it can be a mistake to target reducing hospital deaths as an objective in itself, but rather the ambition must be improving end of life care where ever people are being cared for. While well organised, coordinated and patient centred services can have the effect of reducing hospital deaths, it is not true that somehow forcing fewer deaths in hospital necessarily means improved end of life care.

Slide 22. This is a column chart showing the values for each CCG in order of their proportion of deaths in hospital for the most recent year.

Slide 23. The **role of the community**. Slide 24. Here we look at deaths at home, in care homes and in hospice. Together with a presentation of GP palliative care register data collected for QOF. We are particularly interested in care homes – we know that while many older people make their permanent home in a care home – that is either a residential home or a nursing home; there are others who only find themselves in a nursing home for a short time, perhaps following discharge from hospital and die shortly after. We have been able to estimate who these temporary residents are using the information recorded in the mortality data.

Slide 25. One of the Quality Outcome Framework measures asks GP practices whether they maintain a register of people in need of palliative or end life care support. The return includes the number of patients identified, and our measure attempts to scale this by comparison with the number of people who died. Looking at the box plot, in particular the inter-quartile range, the indicator suggests that there has been a steady rise in the use of registers by GPs – a good thing. The upper whiskers say to me that there is some weird going on in some of the returns – that registers are not maintained similarly across the country. Research has suggested that perhaps a quarter of deaths could be described as unexpected – and so even in the most enthusiastic areas, more than 75 people on the register for every 100 deaths would be surprising – those areas that are more than 75 are maintaining or reporting their register differently than I understand it.

Slide 26. O.K. This is a screen shot of the Interactive Atlas, available on the Right Care web site. It contains all the same data that was used in the pdf, and has behind it the data available in the data download. What this tool adds is the ability to see more clearly the value of a particular indicator at the local level, and to see how it has changed over time.

Slide 27. It's possible to zoom in the map, adjust the boxplot to highlight the values of a particular area and for CCGs compare values to a peer group. I do suggest you check it out and have a play for your self

Slide 28. One of the obvious enquiries about the atlas is the timeliness of data. Unfortunately it has taken us sometime to finish and some of the data does not show the most up to date information for every indicator. The place of death and some of the cause of death measures, together with some of the care home measures are available in the Fingertips End of Life Care Profile and will be updated in due course. We are also planning to update the data in the instant Atlas where we can.

Slide 29. I think I'll stop there, and if you have any questions, I'll do my best to answer them.