

TRANSPLANTATION

Map 22: Variation in rate of liver transplants from all donors per population by CCG (2010/11 - 2014/15)

Crude rate per 1,000,000

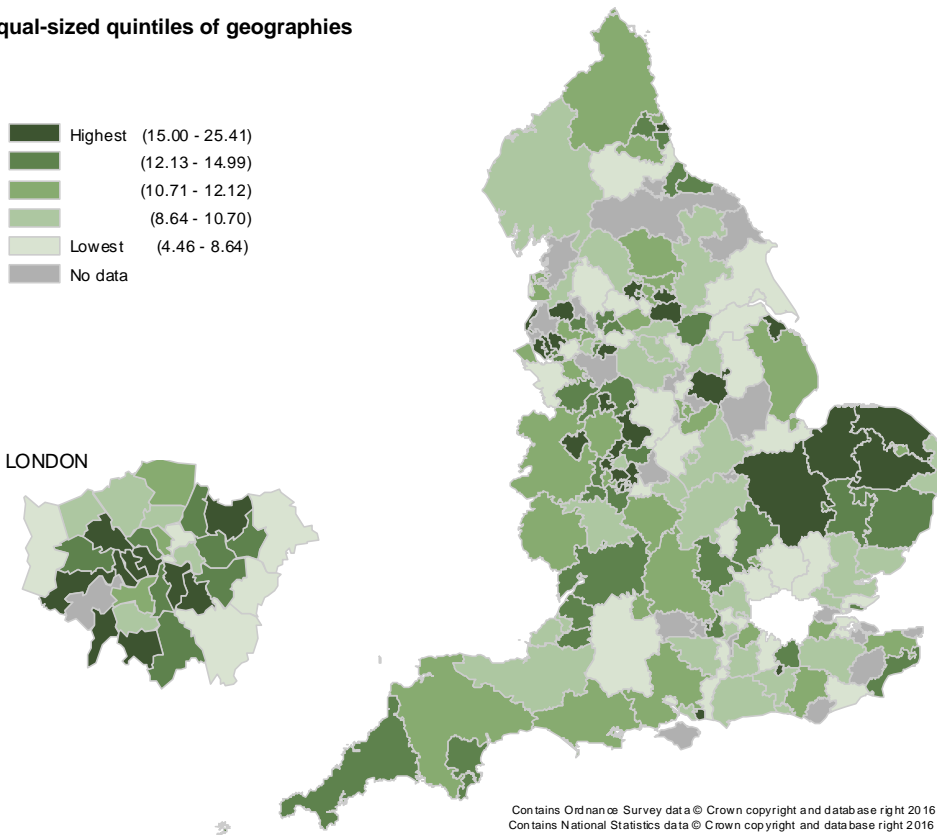
- NHS Domain 1: Preventing people from dying prematurely
- NHS Domain 2: Enhancing quality of life for people with long term conditions
- NHS Domain 3: Helping people to recover from episodes of ill health or following injury
- PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

Equal-sized quintiles of geographies

- Highest (15.00 - 25.41)
- (12.13 - 14.99)
- (10.71 - 12.12)
- (8.64 - 10.70)
- Lowest (4.46 - 8.64)
- No data

LONDON

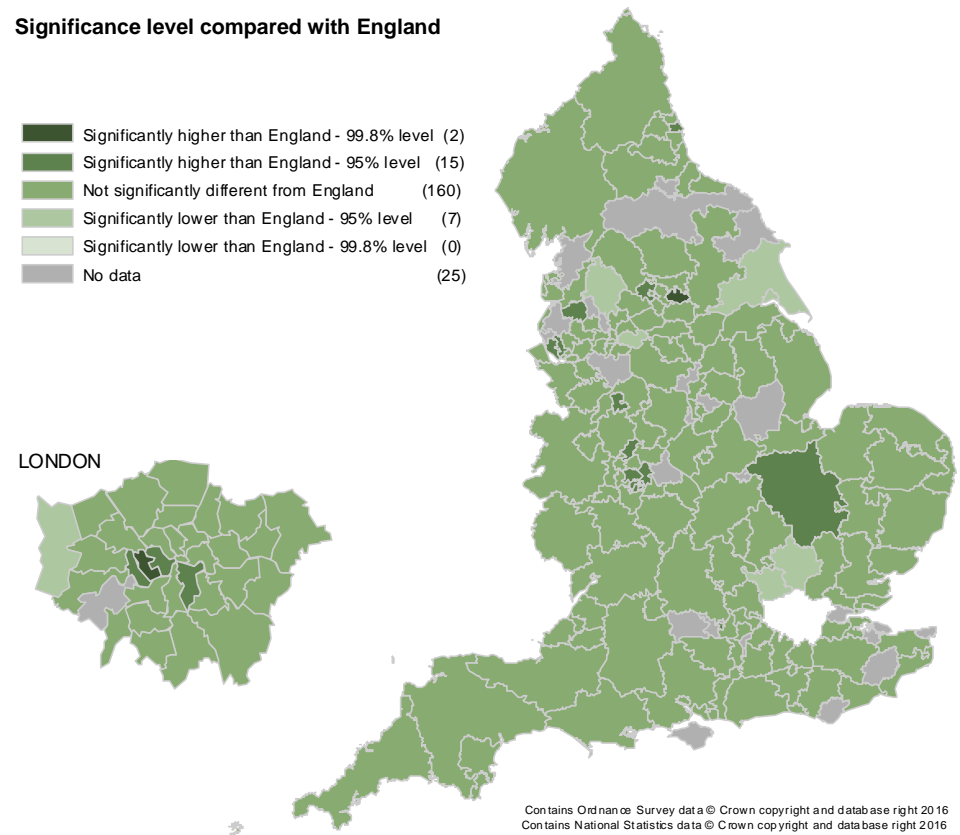


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Significance level compared with England

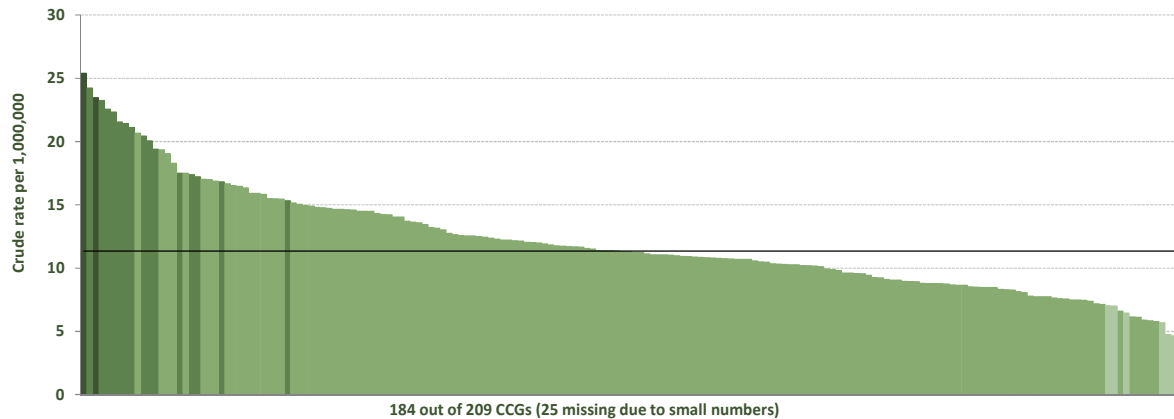
- Significantly higher than England - 99.8% level (2)
- Significantly higher than England - 95% level (15)
- Not significantly different from England (160)
- Significantly lower than England - 95% level (7)
- Significantly lower than England - 99.8% level (0)
- No data (25)

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Variation in rate of liver transplants from all donors per population by CCG (2010/11 - 2014/15)

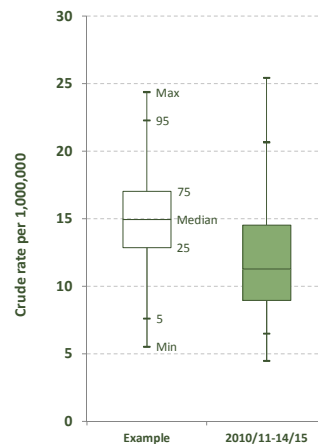


184 out of 209 CCGs (25 missing due to small numbers)

Context

Liver transplantation is a recognised therapy for some patients with end-stage chronic liver disease, and some with sudden acute liver failure and coma, however, most people dying from liver failure are not suitable candidates for liver transplantation. Criteria for selection onto a transplant list have been defined (see 'Resources'), and are reviewed regularly by the Liver Advisory Group for the Directorate of Organ Donation and Transplantation at NHS Blood and Transplant (NHSBT). Criteria for referral for consideration of transplantation are different from those for transplantation.

Selection for a transplant list, once referred, is carefully monitored. There are British Association for the Study of the Liver and NHSBT guidelines for referral to a transplant centre (see 'Resources') to ensure that



Max-Min (Range)		21.0
95th-5th percentile		14.2
75th-25th percentile		5.6
Median		11.3

individuals across the country have equal access to a transplant centre for prompt assessment of their liver disease. NHS Blood and Transplant have developed a universal allocation process, identical in all transplant centres (see 'Resources').

In the UK in 2014/15, 842 liver transplants were performed at six centres in England and one in Scotland as part of the deceased donor liver programme;¹ 38 living-lobe donor transplants and 2 domino donor transplants were also undertaken.¹ Of all liver transplants undertaken in adults in 2014/15, 12% were prioritised as 'super-urgent', where patients need a new liver as soon as possible due to rapid failure of the native organ;¹ the remainder of transplants are considered elective.

Survival following liver transplantation is good: for 2,081 of the 2,227 transplants from 1 April 2010 to 31 March 2014, the overall survival for adults at one year was 92.4%.¹

Demand continues to exceed the supply of organs donated: in 2014/15 more patients were registered for a liver transplant than there were organs available for transplantation.¹ At 31 March 2015 there were 611 patients on the active transplant list;¹ since March 2008 the number of patients on the liver transplant list has doubled.²

At one year post-registration 11% of patients with liver disease had died while waiting for a liver transplant or had been removed from the transplant list due to their condition deteriorating.¹

¹ NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf

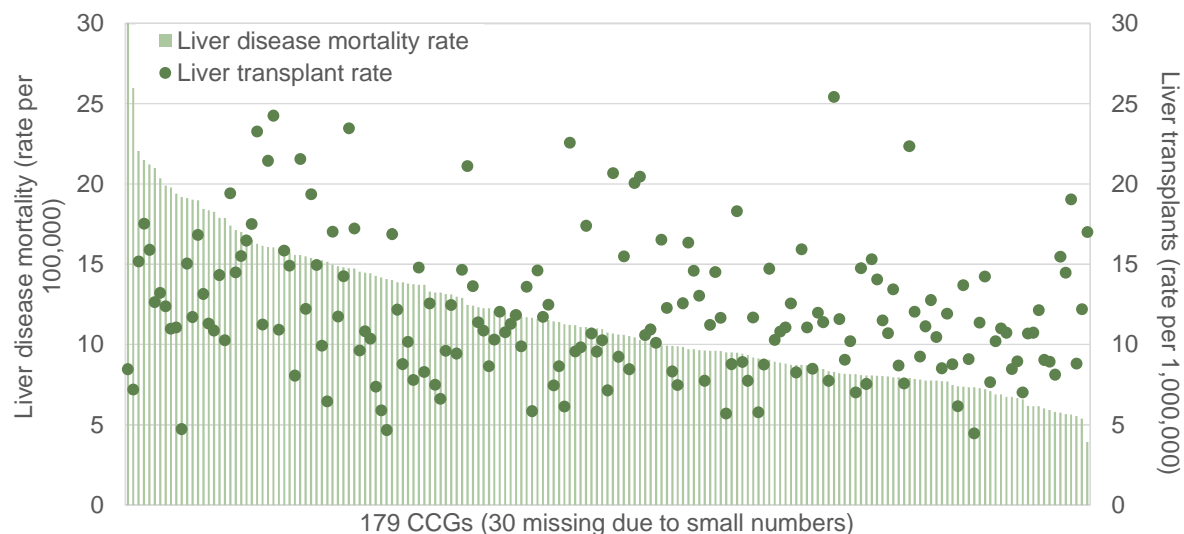
² NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2014/2015 (1 April 2005 – 31 March 2015). Published September 2015. http://odt.nhs.uk/pdf/organ_specific_report_liver_2015.pdf

Magnitude of variation

The maps and column chart display the data for 2010/11 to 2014/15, during which CCG values ranged from 4.5 to 25.4 per million population, which is a 5.7-fold difference between CCGs. The England value for 2010/11 to 2014/15 was 11.4 per million population. The boxplot shows the distribution of CCG values for the period 2010/11 to 2014/15.

In Figure 22.1 the rate of liver transplants (see points) is presented in relation to the mortality rate (directly standardised) from chronic liver disease for people under the age of 75 years (see columns); there appears to be little relationship between mortality rates as an indicator of chronic liver disease prevalence and liver transplantation rates ($r^2=0.0246$).

Figure 22.1: Liver transplant rate per million population 2010/11 to 2014/15 (points) in relation to the rate of chronic liver disease mortality (directly standardised) per 100,000 population aged under 75 years 2013-15 (columns)



Potential reasons for the degree of variation observed include differences in:

- the prevalence of liver disease
- access to expertise in liver disease locally
- local criteria for referral for assessment for liver transplant

- care pathways for people who may require a liver transplant

Options for action

When planning service improvement or development for liver transplantation, commissioners, clinicians and service providers could:

- identify whether there are high liver mortality rates but low transplant rates in the locality, and review local services in relation to the adequacy of expertise in gastroenterology and hepatology and of liaison with transplant centres
- review care pathways for patients with liver disease
- review criteria for selection onto a transplant list to ensure that patients who have the potential to benefit from referral for liver transplantation are considered for the intervention
- where possible, provide transplant assessment services locally, rather than requiring the patient to travel – this could be achieved via outreach networks from transplant and tertiary centres

RESOURCES

- NHS Blood and Transplant. Information concerning transplant activity by centre and nationally. www.organdonation.nhs.uk/statistics/
- NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
- British Association for the Study of the Liver and NHS Blood and Transplant. Guidelines for Referral for Liver Transplant Assessment. March 2012.

- http://odt.nhs.uk/pdf/advisory_group_papers/LAG/referral_for_transplantation.pdf
- NHS Blood and Transplant. Introduction to Patient Selection and Organ Allocation Policies. Policy POL200/3. Effective 08/12/2015.
http://odt.nhs.uk/pdf/introduction_to_selection_and_allocation_policies.pdf
 - Liver Advisory Group on behalf of NHS Blood and Transplant. Liver Transplantation: Selection Criteria and Recipient Registration. Policy POL195/6. Effective 02/05/17.
http://odt.nhs.uk/pdf/liver_selection_policy.pdf
 - Liver Advisory Group on behalf of NHS Blood and Transplant. Deceased Donor Liver Distribution and Allocation. Policy POL196/4.1. Effective 14/12/2015.
http://odt.nhs.uk/pdf/liver_allocation_policy.pdf
 - NHS England. Schedule 2 – The Services. A. Service Specifications. 170003/S. Liver Transplantation service (Adults). www.england.nhs.uk/wp-content/uploads/2017/04/liver-transplantation-service-adults.pdf
 - NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2014/2015 (1 April 2015 – 31 March 2015). Published September 2015. http://odt.nhs.uk/pdf/organ_specific_report_liver_2015.pdf
 - NICE. Living-donor liver transplantation. Interventional procedures guidance [IPG535]. Published date: November 2015. www.nice.org.uk/guidance/ipg535

TRANSPLANTATION

Map 23a: Variation in rate of organ donation from deceased donors per population by Strategic Health Authority (2014/15)

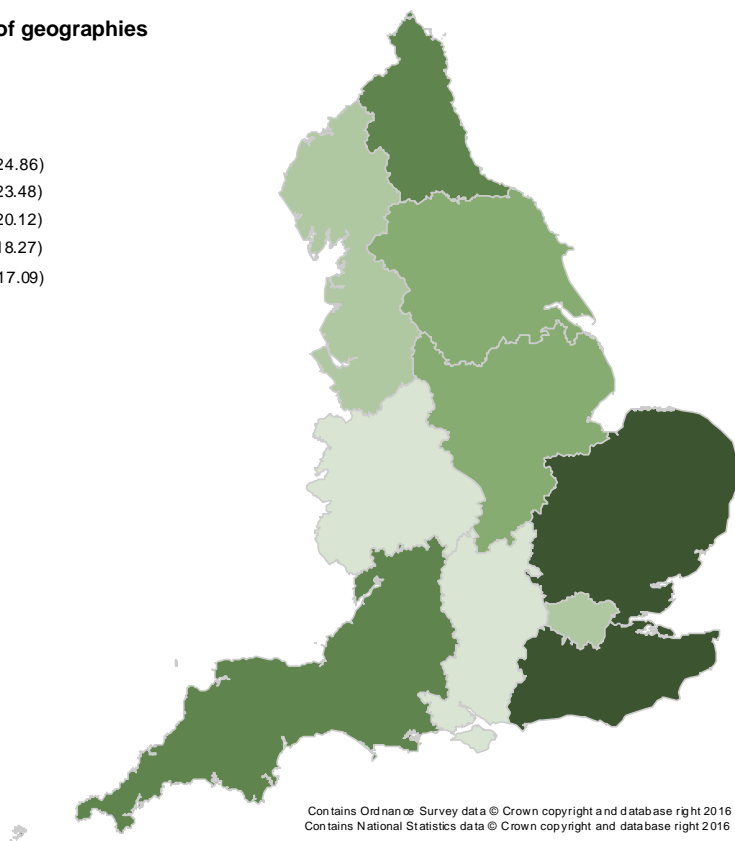
Crude rate per 1,000,000

- NHS Domain 1: Preventing people from dying prematurely
- NHS Domain 2: Enhancing quality of life for people with long-term conditions
- NHS Domain 3: Helping people to recover from episodes of ill health or following injury
- PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

Equal-sized quintiles of geographies

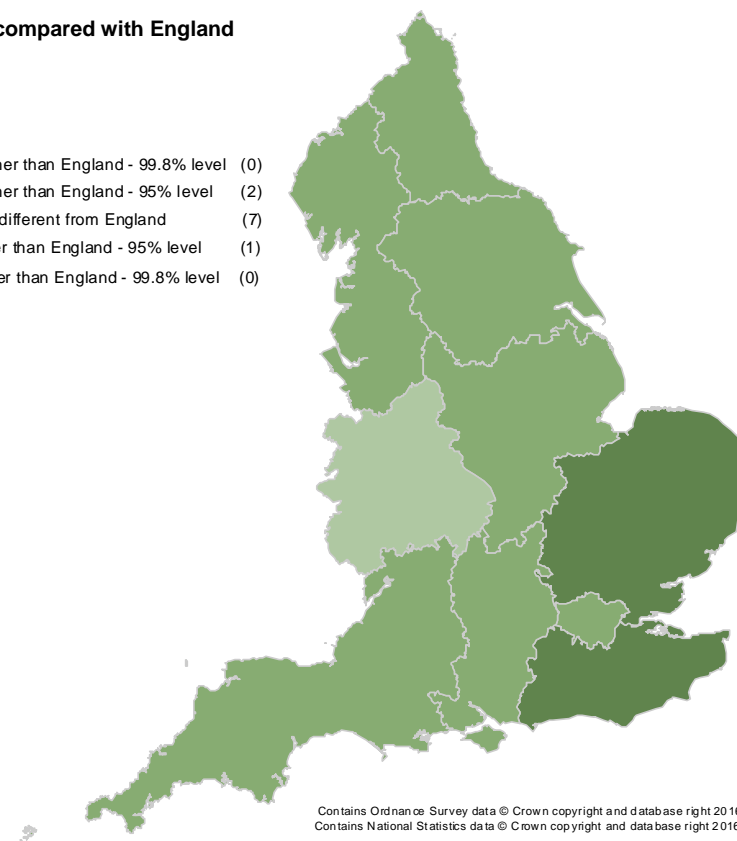
- Highest (23.49 - 24.86)
- (20.13 - 23.48)
- (18.28 - 20.12)
- (17.10 - 18.27)
- Lowest (15.40 - 17.09)



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Significance level compared with England

- Significantly higher than England - 99.8% level (0)
- Significantly higher than England - 95% level (2)
- Not significantly different from England (7)
- Significantly lower than England - 95% level (1)
- Significantly lower than England - 99.8% level (0)



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TRANSPLANTATION

Map 23b: Variation in rate of liver donation from deceased donors per population by Strategic Health Authority (2014/15)

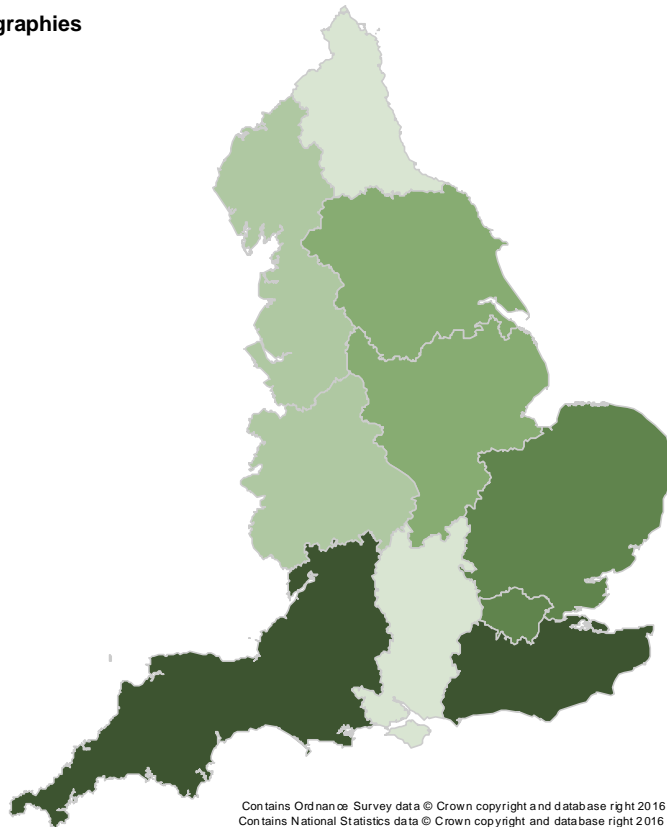
Crude rate per 1,000,000

- NHS Domain 1: Preventing people from dying prematurely
- NHS Domain 2: Enhancing quality of life for people with long-term conditions
- NHS Domain 3: Helping people to recover from episodes of ill health or following injury
- PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

Equal-sized quintiles of geographies

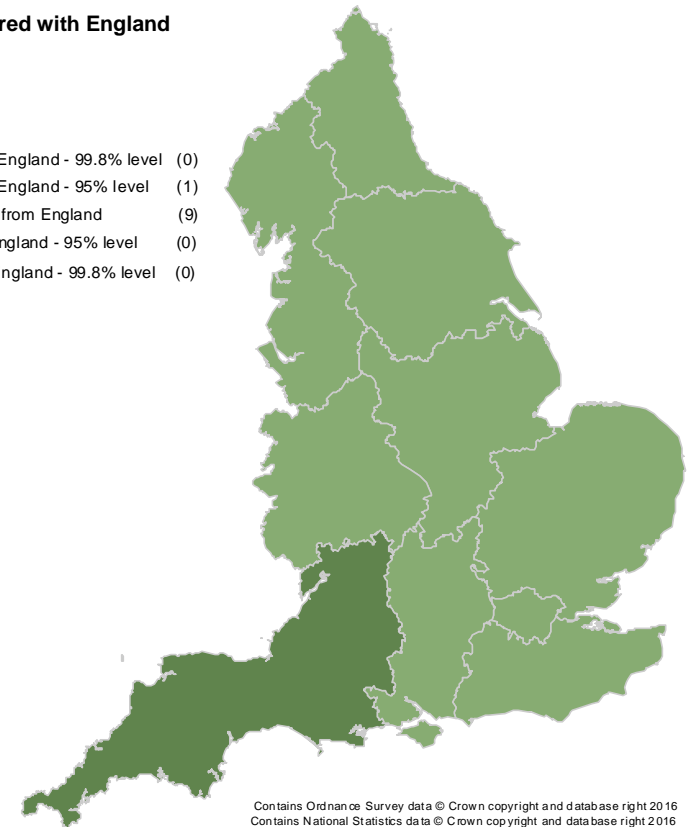
- Highest (15.60 - 17.32)
- (13.90 - 15.59)
- (12.49 - 13.89)
- (12.04 - 12.48)
- Lowest (11.78 - 12.03)



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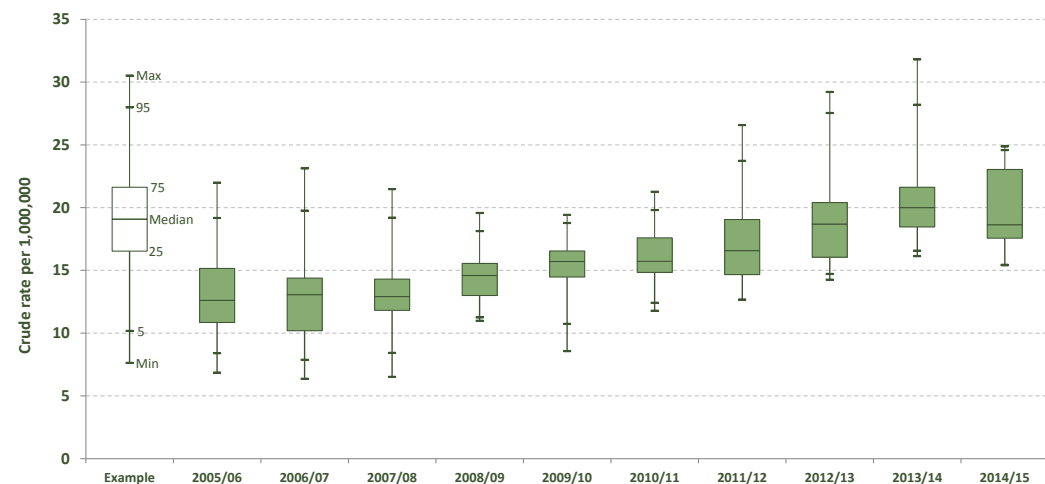
Significance level compared with England

- Significantly higher than England - 99.8% level (0)
- Significantly higher than England - 95% level (1)
- Not significantly different from England (9)
- Significantly lower than England - 95% level (0)
- Significantly lower than England - 99.8% level (0)



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Variation in rate of organ donation from deceased donors per population by Strategic Health Authority (2014/15)



	Example	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	
Max-Min (Range)		15.1	16.8	15.0	8.6	10.9	9.5	13.9	15.0	15.7	9.5	No significant change
95th-5th percentile		10.8	11.9	10.8	6.9	8.0	7.4	11.1	12.8	11.6	9.1	No significant change
75th-25th percentile		4.3	4.2	2.5	2.6	2.1	2.7	4.4	4.3	3.2	5.5	No significant change
Median		12.6	13.1	12.9	14.6	15.7	15.7	16.6	18.7	20.0	18.6	INCREASING Significant

Context

In the Activity Report for 2015/16, NHS Blood and Transplant (NHSBT) highlight that organ donation is a relatively rare event.¹ Although about 500,000 people die in the UK each year, very few die in circumstances that enable their organs to be donated.¹ The collaborative UK strategy ‘Taking Organ Donation to 2020’ (see ‘Resources’) implemented in 2013, between the four UK health departments and NHSBT, was developed to increase the number of people who donate their organs after death.

The aims of NICE guidance on organ donation for transplantation (CG135; see ‘Resources’) are:

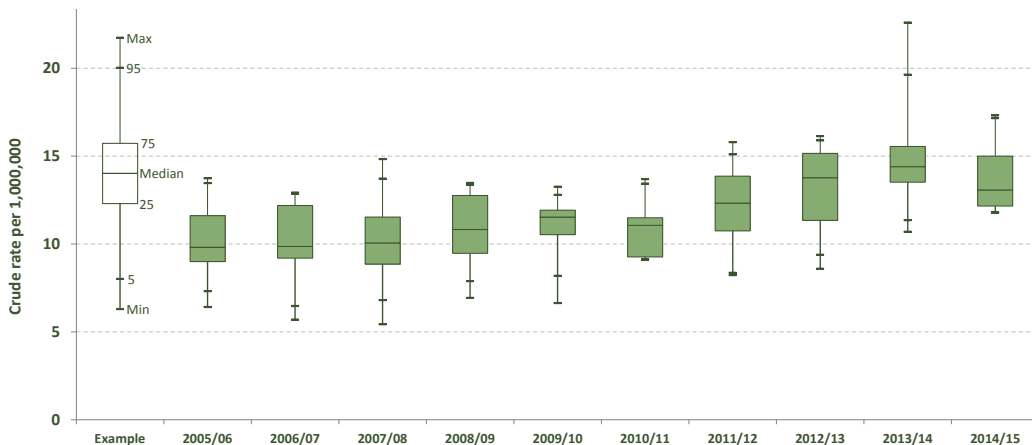
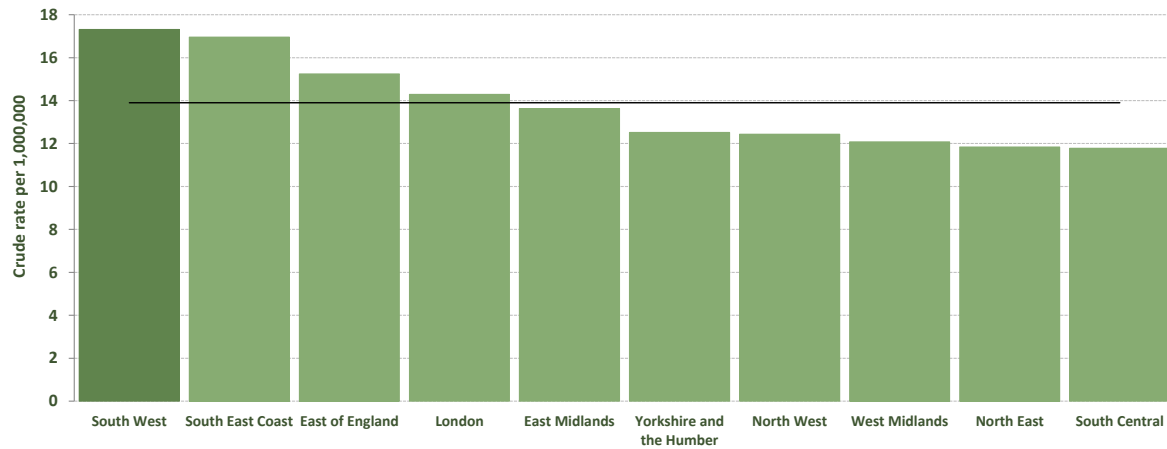
- to promote discussion of organ donation as an integral part of end-of-life care
- to increase the number of organs available for people waiting for a transplant

In 2015/16 in England 1,134 people donated organs after their death, a rate of 20.9 per million population.¹ Although this represents an increase in the number of donors after death since 2008, the increase is mainly due to the expansion of programmes for donation after circulatory death and not to an increase in family consent rate. The UK has one of the lowest rates of family consent in countries with developed economies.² During 2015/16, 479 patients in the UK died while active/suspended on the transplant list or within one year of removal from the list.¹

¹ NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf

² The Scottish Government, Welsh Government, Department of Health, Department of Health, Social Services and Public Safety and NHS Blood and Transplant. Taking Organ Transplantation to 2020: A detailed strategy. [Not dated] www.nhsbt.nhs.uk/to2020/the-strategy

Variation in rate of liver donation from deceased donors per population by Strategic Health Authority (2014/15)



	Example	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	
Max-Min (Range)		7.3	7.2	9.4	6.5	6.6	4.6	7.6	7.5	11.9	5.5	No significant change
95th-5th percentile		6.2	6.4	6.9	5.5	4.6	4.3	6.7	6.5	8.3	5.3	No significant change
75th-25th percentile		2.6	3.0	2.7	3.3	1.4	2.2	3.1	3.8	2.0	2.8	No significant change
Median		9.8	9.9	10.1	10.8	11.5	11.1	12.3	13.8	14.4	13.1	INCREASING Significant

The low consent rate is a challenge for all of society: improving the consent rate is the best opportunity to increase donor rates.² It is particularly important to increase donation rates in people from Black, Asian and minority ethnic (BAME) communities because the need for kidney transplants is high in these population groups: BAME groups in the UK represent 27% of people on the kidney transplant waiting list but only 5% of organ donors.²

There are two types of organ donation after death: donation after brain death (referred to as DBD) and donation after circulatory death (referred to as DCD). NHS Blood and Transplant defines eligible donors:

- after brain death as patients for whom death was confirmed following neurological tests and who had no absolute medical contraindications to solid organ donation¹
- after circulatory death as patients who had treatment withdrawn and death was anticipated within four hours, with no absolute medical contraindications to solid organ donation¹

Overall, on average, donors after circulatory death provide one less organ for transplantation than donors after brain death.¹ In England in 2015/16 the average number of organs donated per adult donor was 2.8 for circulatory death and 3.8 for brain death, partly because only 12% of donors after brain death were single-organ donors versus 47% of donors after circulatory death.¹

Donor characteristics are changing: when compared with 2006/07, donors in 2015/16 tend to be older, more obese, less likely to have suffered a trauma-related death and more likely to have a more complex medical history, all of

which may have an adverse impact on the quality of organs and subsequent transplant outcomes.¹

In 2015/16 for donors after brain death in the UK:

- the mean age was 51 years
- the mean body mass index (BMI) was 27¹

In 2015/16 for donors after circulatory death in the UK:

- the mean age was 52 years
- the mean BMI was 27¹

In 2015/16 in the UK only 6% of donors after brain death and only 3% of donors after circulatory death were from BAME groups, whereas these groups comprise 11% of the UK population.¹

Focusing on liver donation from deceased donors in England in 2015/16, 845 donors donated their liver for transplant, a rate of 15.6 per million population: 597 were donors after brain death (11.0 per million population) and 248 were donors after circulatory death (4.6 per million population).¹ The mean age of deceased liver donors in the UK in 2015/16 was 50 years, and 5% of the deceased liver donors were from BAME groups.¹

Magnitude of variation

Map 23a: Organ donation from deceased donors

The maps and column chart display the data for 2014/15, during which SHA values ranged from 15.4 to 24.9 per million population, which is a 1.6-fold difference between SHAs. The England value for 2014/15 was 19.5 per million population.

The boxplot shows the distribution of SHA values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15. The median increased significantly from 12.6 in 2005/06 to 18.6 per million population in 2014/15.

Map 23b: Liver donation from deceased donors

The maps and column chart display the data for 2014/15, during which SHA values ranged from 11.8 to 17.3 per million population, which is a 1.5-fold difference between SHAs. The England value for 2014/15 was 13.9 per million population.

The boxplot shows the distribution of SHA values for the period 2005/06 to 2014/15.

There was no significant change in any of the three variation measures between 2005/06 and 2014/15

The median increased significantly from 9.8 in 2005/06 to 13.1 per million population in 2014/15.

In a systematic review the following factors were found to affect views on organ donation after death:

- personal religious beliefs
- personal cultural beliefs
- family relationships
- knowledge of the organ donation process
- attitudes towards the healthcare system³

Options for action

NICE Guidance (CG135; see 'Resources') stipulates that every hospital should have a policy and protocol consistent with NICE recommendations for identifying patients who are potential donors and managing the consent process for deceased organ donation. In particular, service providers need:

³ Irving MJ, Tong A, Jan S et al. Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology Dialysis Transplantation* 2012; 27: 2526-2533.

- to develop an approach where organ donation is viewed as a routine component of planning for end-of-life care
- using criteria laid out in NICE guidance CG135 to identify systematically patients who are potentially suitable donors as early as possible
- to ensure that healthcare teams caring for patients who are potentially suitable organ donors initiate discussions about potential organ donation with the specialist nurse for organ donation at the point in time when the criteria in NICE guidance CG135 have been met
- to ensure that multidisciplinary teams responsible for identification, referral and consent processes have the necessary skills and competencies, including knowledge of the basic principles and relative benefits of donation after brain death and donation after circulatory death, an understanding of the principles of the diagnosis of death using neurological or cardiorespiratory criteria and how they relate to the organ donation process, an ability to explain neurological death clearly to families, an understanding of the processes, policies and protocols relating to donor management and an ability to adhere to professional standards of practice about organ donation and end-of-life care
- to ensure consultant staff have the specific skills and knowledge needed, including knowledge of the law governing organ donation, knowledge of medical ethics relating to organ donation and skills in the diagnosis and confirmation of death using neurological or cardiorespiratory criteria

According to NICE guidance (CG135; see 'Resources') further research is needed to identify:

- why families refuse to give permission for organ donation
- the key components of an intervention aimed at improving rates of identification and the referral of potential donors
- the key components of an intervention aimed at improving consent rates
- whether a positive experience of approach and process of consent for families can increase the consent rate

RESOURCES

- The Scottish Government, Welsh Government, Department of Health, Department of Health, Social Services and Public Safety and NHS Blood and Transplant. Taking Organ Transplantation to 2020: A detailed strategy. www.nhsbt.nhs.uk/to2020/the-strategy
- NICE. Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. Clinical guideline [CG135]. Published date: December 2011. Last updated: December 2016. www.nice.org.uk/guidance/cg135
- NICE interactive flowchart. Organ donation for transplantation overview. <https://pathways.nice.org.uk/pathways/organ-donation-for-transplantation>
- NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf
- NHS Blood and Transplant. Organ Donation and Transplantation: Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
- NHS Blood and Transplant. Caring for Multi-Ethnic Communities: Religion, Culture and Organ Donation. http://odt.nhs.uk/pdf/caring_for_multi_ethnic_communities.pdf

TRANSPLANTATION

Map 24: Variation in rate of liver transplants from deceased donors per population by Strategic Health Authority (2014/15)

Crude rate per 1,000,000

NHS Domain 1: Preventing people from dying prematurely

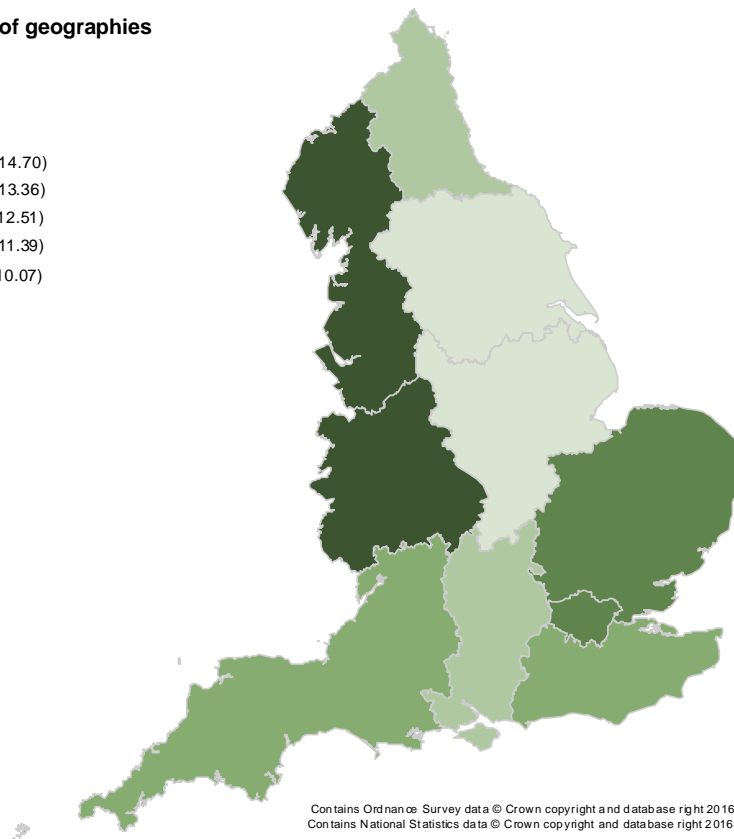
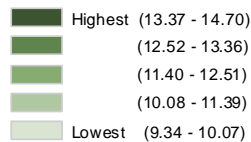
NHS Domain 2: Enhancing quality of life for people with long term conditions

NHS Domain 3: Helping people to recover from episodes of ill health or following injury

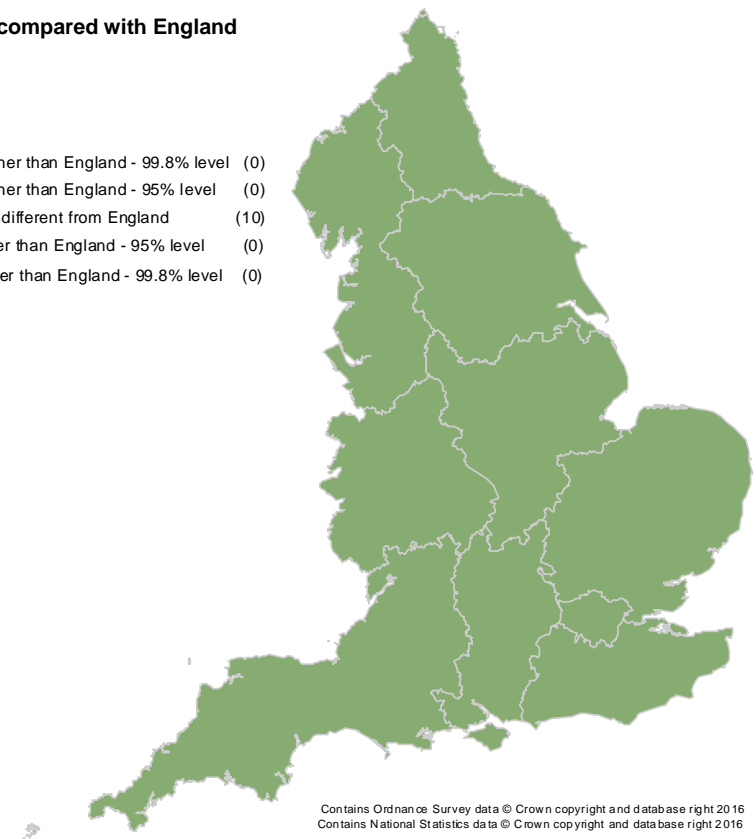
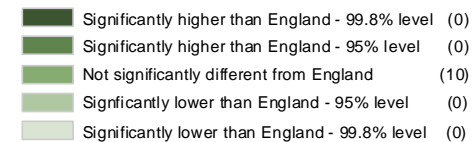
PHOF Domain 4: Healthcare public health and preventing mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

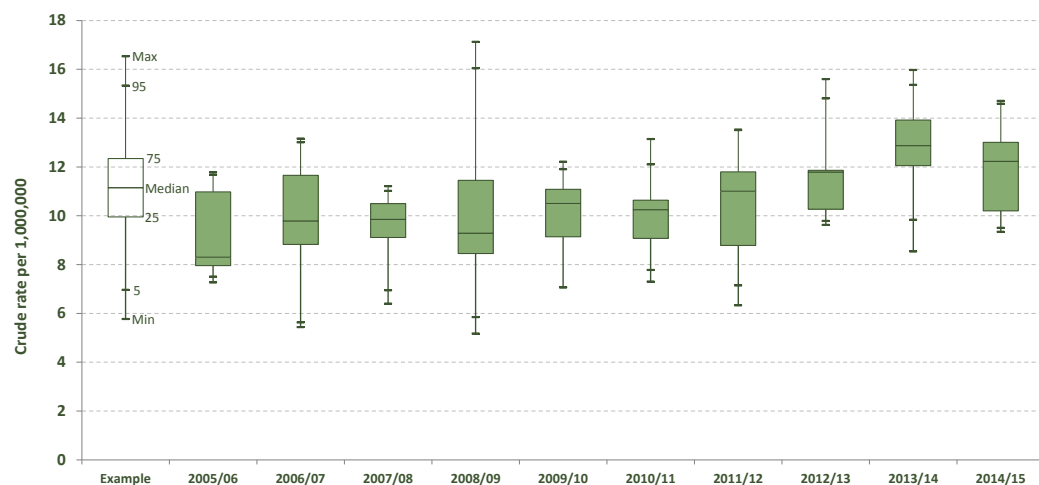
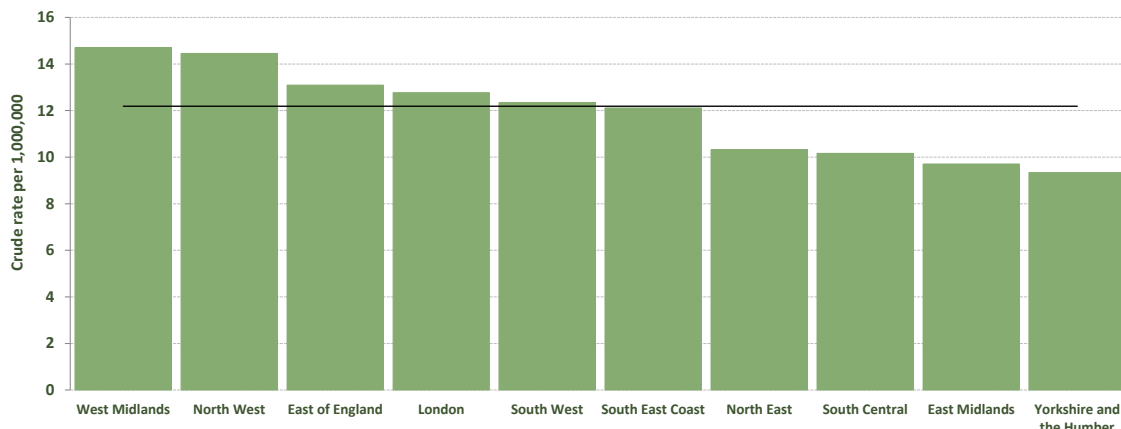
Equal-sized quintiles of geographies



Significance level compared with England



Variation in rate of liver transplants from deceased donors per population by Strategic Health Authority (2014/15)



	Example	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	
Max-Min (Range)		4.5	7.7	4.8	12.0	5.2	5.8	7.2	6.0	7.4	5.4	No significant change
95th-5th percentile		4.2	7.4	4.1	10.2	4.8	4.3	6.4	5.0	5.5	5.1	No significant change
75th-25th percentile		3.0	2.8	1.4	3.0	1.9	1.6	3.0	1.6	1.9	2.8	No significant change
Median		8.3	9.8	9.9	9.3	10.5	10.3	11.0	11.8	12.9	12.2	INCREASING Significant

Context

Liver transplantation is a recognised therapy for some patients with end-stage chronic liver disease, and some with sudden acute liver failure and coma, however, most people dying from liver failure are not suitable candidates for liver transplantation. The criteria for selection onto a transplant list have been defined (see 'Resources'), and are reviewed regularly by the Liver Advisory Group for the Directorate of Organ Donation and Transplantation at NHS Blood and Transplant (NHSBT). Criteria for referral for consideration of transplantation are different from those for transplantation.

Selection for a transplant list, once referred, is carefully monitored. There are British Association for the Study of the Liver and NHSBT guidelines for referral to a transplant centre (see 'Resources') to ensure that individuals across the country have equal access to a transplant centre for prompt assessment of their liver disease. NHS Blood and Transplant have developed a universal allocation process, identical in all transplant centres (see 'Resources').

In the UK in 2014/15 the number of liver donors:

- after brain death was 684¹, which increased by 5% to 715 in 2015/16²
- after circulatory death was 240¹, which increased by 23% to 296 in 2015/16²

In the UK in 2014/15, 842 liver transplants were performed at six centres in England and one in Scotland as part of the

¹ NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf

² NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf

deceased donor liver programme¹ compared with 878 in 2015/16².

In 2014/15 the number of transplants from donors after brain death was 665¹ compared with 672 in 2015/16, an increase of 1%², whereas the number of transplants from donors after circulatory death was 177 in 2014/15¹ compared with 206 in 2015/16, an increase of 16%².

Of all liver transplants undertaken in adults in 2014/15 and in 2015/16, 12% were prioritised as 'super-urgent'^{1,2}, where patients need a new liver as soon as possible due to rapid failure of the native organ; the remainder of transplants are considered elective.

Survival following liver transplantation in the UK is good: for 2,141 transplants from 1 April 2011 to 31 March 2015, one-year survival for adult elective first transplants (unadjusted) was 93.4%.³

Demand continues to exceed the supply of organs donated: in 2014/15 more patients were registered for a liver transplant than there were organs available for transplantation.¹ At 31 March 2015 there were 611 patients on the active transplant list¹ compared with 584 at 31 March 2016, a decrease of 4%.² Since March 2008, however, the number of patients on the liver transplant list has doubled.³

In 2014/15 at one year post-registration 11% of patients with liver disease died while waiting for a liver transplant, or had been removed from the transplant list due to their condition deteriorating,¹ compared with 9% in 2015/16.²

Magnitude of variation

The maps and column chart display the data for 2014/15, during which SHA values ranged from 9.3 to 14.7 per million population, which is a 1.6-fold difference between SHAs. The England value for 2014/15 was 12.2 per million population.

The boxplot shows the distribution of SHA values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15. The median increased significantly from 8.3 in 2005/06 to 12.2 per million population in 2014/15.

Potential reasons for the degree of variation observed include differences in:

- the prevalence of liver disease

- access to expertise in liver disease locally
- criteria for referral for assessment for liver transplant
- care pathways for people who may require a liver transplant

Options for action

When planning service improvement or development for liver transplantation, commissioners, clinicians and service providers could:

- identify whether there are high mortality rates from liver disease but low transplant rates in the locality, and review local services in relation to the adequacy of expertise in gastroenterology and hepatology and of liaison with transplant centres
- review care pathways for patients with liver disease
- review criteria for selection onto a transplant list to ensure that patients who have the potential to benefit from referral for liver transplantation are considered for the intervention
- where possible, provide transplant assessment services locally rather than requiring patients to travel – this could be achieved via outreach networks from transplant and tertiary centres

RESOURCES

- NHS Blood and Transplant. Information concerning transplant activity by centre and nationally. www.organdonation.nhs.uk/statistics
- British Association for the Study of the Liver and NHS Blood and Transplant. Guidelines for Referral for Liver Transplant Assessment. March 2012.

³ NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2015/2016 (1 April 2006 – 31 March 2016). Published September 2016. https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/1314/organ_specific_report_liver_2016.pdf

- http://odt.nhs.uk/pdf/advisory_group_papers/LAG/referral_for_transplantation.pdf
- NHS Blood and Transplant. Introduction to Patient Selection and Organ Allocation Policies. Policy POL200/3. Effective 08/12/2015. https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/4357/introduction_to_selection_and_allocation_policies.pdf
 - Liver Advisory Group on behalf of NHS Blood and Transplant. Liver Transplantation: Selection Criteria and Recipient Registration. Policy POL195/6. Effective 02/05/17. http://odt.nhs.uk/pdf/liver_selection_policy.pdf
 - Liver Advisory Group on behalf of NHS Blood and Transplant. Deceased Donor Liver Distribution and Allocation. Policy POL196/4.1. Effective 14/12/2015. http://odt.nhs.uk/pdf/liver_allocation_policy.pdf
 - NHS England. Schedule 2 – The Services. A. Service Specifications. 170003/S. Liver Transplantation service (Adults). www.england.nhs.uk/wp-content/uploads/2017/04/liver-transplantation-service-adults.pdf
 - NHS Blood and Transplant. Produced in collaboration with NHS England. Annual Report on Liver Transplantation. Report for 2014/2015 (1 April 2015 – 31 March 2015). Published September 2015. https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/1314/organ_specific_report_liver_2016.pdf
 - NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2014/15. http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf
 - NHS Blood and Transplant. Organ Donation and Transplantation. Activity Report 2015/16. https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/1452/activity_report_2015_16.pdf

MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 25: Variation in percentage of admissions for oesophageal varices procedure that were emergency admissions by CCG (2014/15)

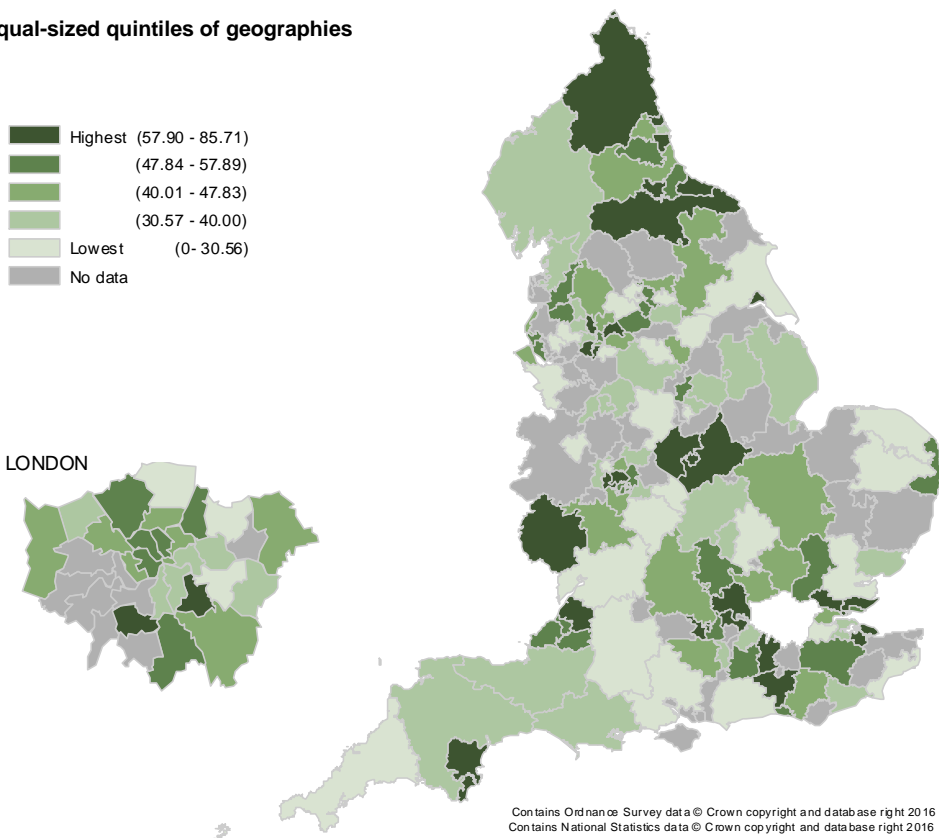
NHS Domain 1: Ensuring that people have a positive experience of care
 NHS Domain 3: Helping people to recover from episodes of ill health or following injury
 PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

Equal-sized quintiles of geographies

- Highest (57.90 - 85.71)
- (47.84 - 57.89)
- (40.01 - 47.83)
- (30.57 - 40.00)
- Lowest (0 - 30.56)
- No data

LONDON

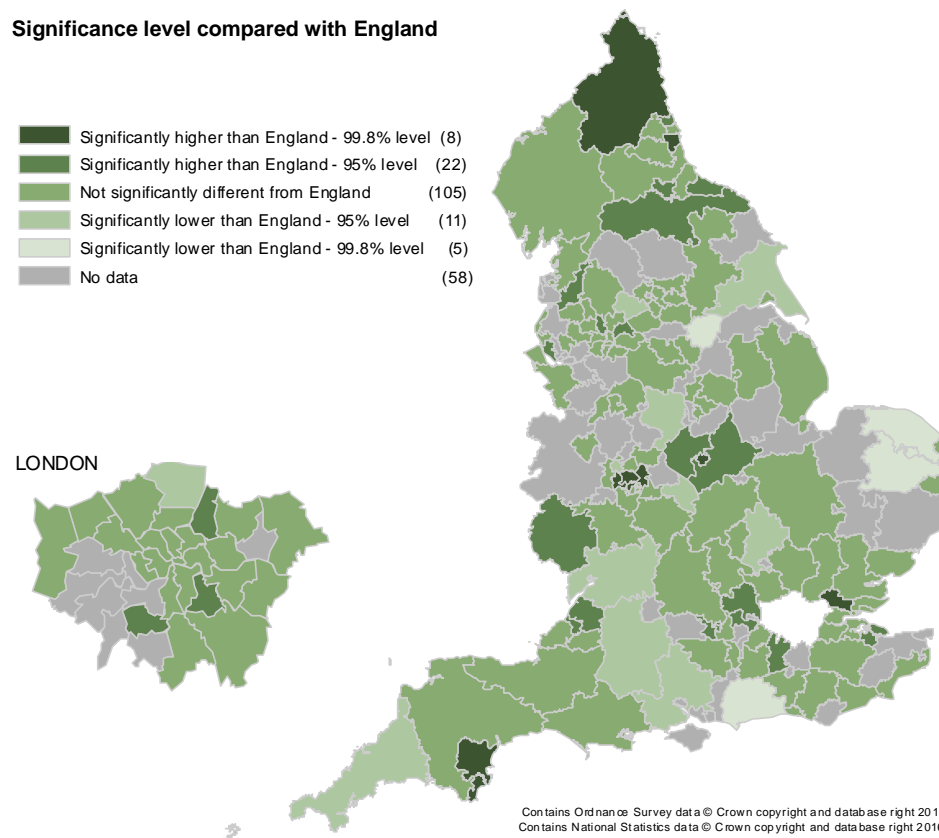


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Significance level compared with England

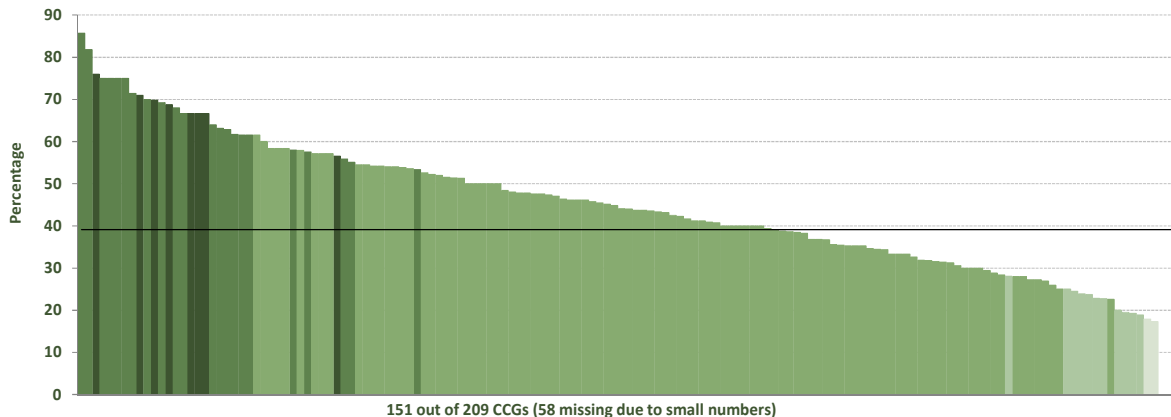
- Significantly higher than England - 99.8% level (8)
- Significantly higher than England - 95% level (22)
- Not significantly different from England (105)
- Significantly lower than England - 95% level (11)
- Significantly lower than England - 99.8% level (5)
- No data (58)

LONDON

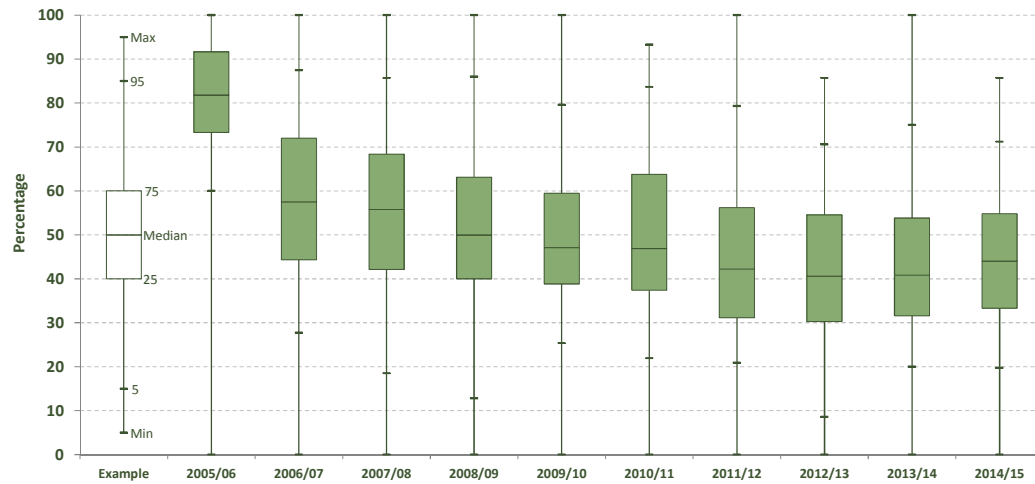


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Variation in percentage of admissions for oesophageal varices procedure that were emergency admissions by CCG (2014/15)



151 out of 209 CCGs (58 missing due to small numbers)



	Example	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	
Max-Min (Range)		100.0	100.0	100.0	100.0	100.0	93.3	100.0	85.7	100.0	85.7	No significant change
95th-5th percentile		40.0	59.8	67.2	73.3	54.3	61.7	58.4	62.0	55.0	51.4	No significant change
75th-25th percentile		18.3	27.7	26.3	23.1	20.6	26.4	25.1	24.2	22.3	21.5	No significant change
Median		81.8	57.5	55.8	50.0	47.1	46.9	42.2	40.6	40.8	44.0	DECREASING Significant

Context

Varices are blood vessels which form as a consequence of portal hypertension (high pressure in the portal vein - the main blood supply to the liver). This is most commonly caused by scarring from cirrhosis. Varices can occur throughout the GI tract however are most commonly found in the lower oesophagus. Varices are at risk of bleeding, which can vary in severity from a small ooze to a life threatening haemorrhage.¹

The majority of patients with variceal bleeding have chronic liver disease, and oesophageal varices are a significant complication of cirrhosis. Although there are many causes of cirrhosis, alcohol consumption is the most common in the UK. NASH, viral hepatitis and autoimmune disorders are the next most common.

The size of the varices is directly related to the blood pressure in the portal vein, which in most cases is directly related to the severity of the underlying liver disease. Portal hypertension is seen in people with moderately advanced liver disease, which may be accompanied by other symptoms such as ascites (fluid in the abdomen; see Map 26) and encephalopathy (disturbance of brain function as a result of the impaired ability of the liver to detoxify proteins).

Vomiting blood secondary to varices is a sign of advanced cirrhosis of the liver. If bleeding occurs, it is characteristically severe, can be life-threatening and therefore requires urgent medical attention. Early intervention is usually effective and reduces the risk of further complications.

¹ British Liver Trust. Portal Hypertension. www.britishlivertrust.org.uk/liver-information/liver-conditions/portal-hypertension/. Accessed 5th June 2017.

Several procedures can be used to stop the bleeding and reduce the risk of recurrence:

- Drug treatment with terlipressin by intravenous injection
- Banding – using endoscopy a small band is inserted around the base of the varix to control the bleeding
- Injection sclerotherapy – during endoscopy a sclerosant material is injected into the varices to induce blood-clotting and thereby stop the bleeding
- Transjugular intrahepatic portosystemic stent shunt (TIPSS), in which a stent is radiologically cited between hepatic and portal veins to reduce portal pressure and thereby reduce the risk of bleeding and/or the severity of a bleed

The use of the Sengstaken tube, where the tube is passed into the stomach and inflated putting pressure on the varices to stop the bleeding is now much rarer since the advent of the endoscopy.

Unless oesophageal varices bleed, they do not generate any other signs or symptoms. It is possible to quantify size and location of varices using endoscopy.

It is possible to reduce the risk of variceal bleeding through the use of beta blockers, such as propranolol, which reduce portal pressure. Drug treatment can also be used to reduce the severity of a bleed should one occur.

Primary prophylaxis of variceal bleeding reduces risk of haemorrhage. This can be achieved using drug treatments (e.g. propranolol) to reduce pressure in the portal vein, or through an elective programme of variceal band ligation.

Magnitude of variation

The maps and column chart display the 2014/15 data, during which CCG values ranged from 0.0% to 85.7%. The England value for 2014/15 was 39.1%.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15, however the median decreased significantly from 81.8% in 2005/06 to 44.0% in 2014/15.

Potential reasons for the degree of variation observed include differences in:

- the organisation of services

- the availability of specialists

Options for action

When planning service improvement or development to reduce emergency admissions for oesophageal varices, commissioners, clinicians and service providers need:

- to review the emergency admission rate for oesophageal varices in the locality
- to identify opportunities for improving the early diagnosis of cirrhosis and other types of liver damage
- to improve the prevention and treatment of oesophageal varices
- to review the clinical management of and configuration of services for liver disease to ensure close collaboration among the different disciplines – hepatology, diagnostic pathology and radiology services, interventional radiology and liver surgery including resection and transplantation

RESOURCES

- Tripathi D, et al. UK guidelines on the management of variceal haemorrhage in cirrhotic patients. *Gut* 2015;64:1680–1704. <http://dx.doi.org/10.1136/gutjnl-2015-309262>
- BMJ Best Practice. Oesophageal varices – management approach. Updated Jan 12 2017. <http://bestpractice.bmj.com/best-practice/monograph/815/treatment/step-by-step.html>
- NICE. Cirrhosis in over 16s: assessment and management. NICE guideline [NG50]. July 2016. www.nice.org.uk/guidance/ng50
- NICE. NICE Interactive pathway. Cirrhosis overview. <https://pathways.nice.org.uk/pathways/cirrhosis>

MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

Map 26: Variation in percentage of admissions for paracentesis procedure that were emergency admissions by CCG (2014/15)

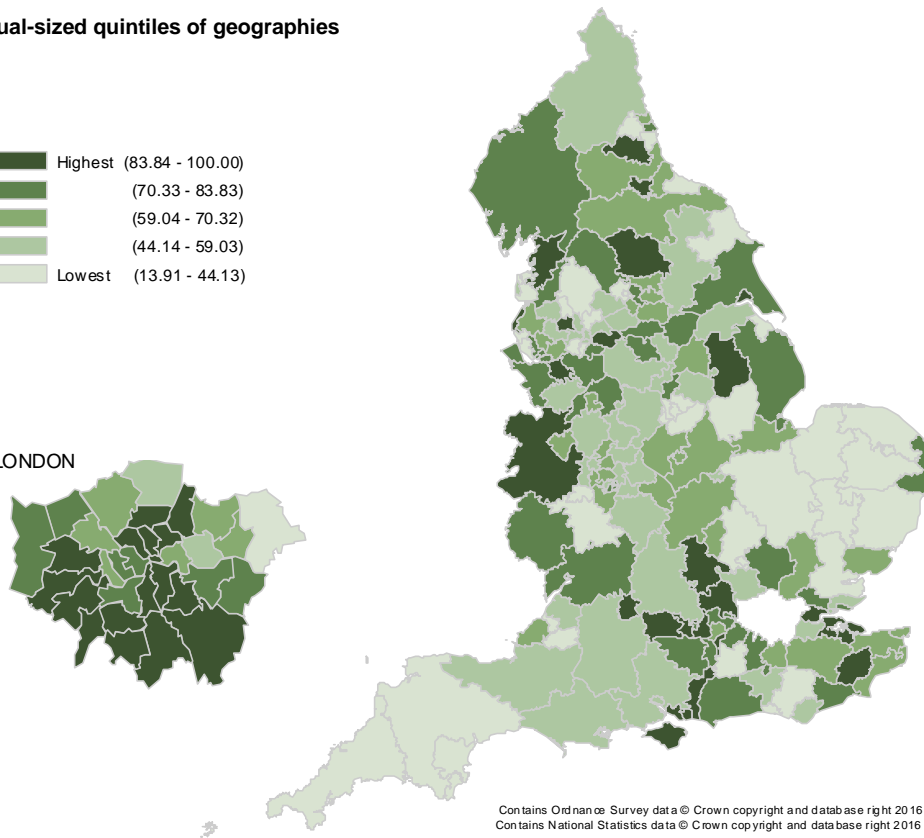
NHS Domain 1: Ensuring that people have a positive experience of care
 NHS Domain 3: Helping people to recover from episodes of ill health or following injury
 PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

Equal-sized quintiles of geographies

- Highest (83.84 - 100.00)
- (70.33 - 83.83)
- (59.04 - 70.32)
- (44.14 - 59.03)
- Lowest (13.91 - 44.13)

LONDON

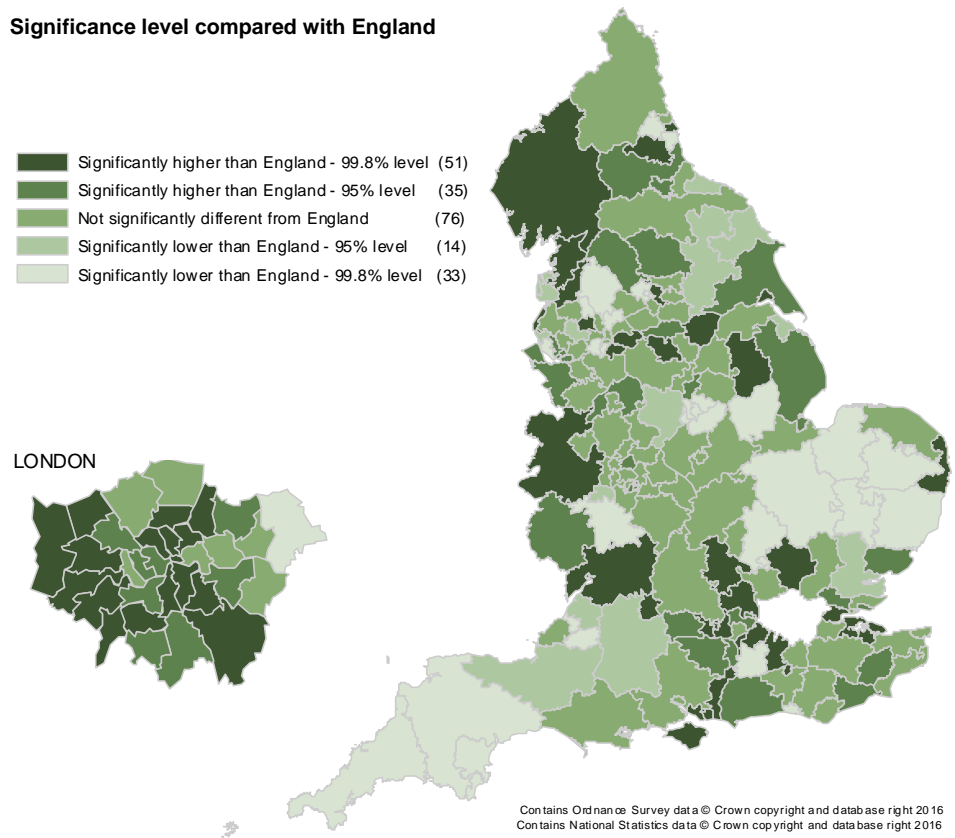


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Significance level compared with England

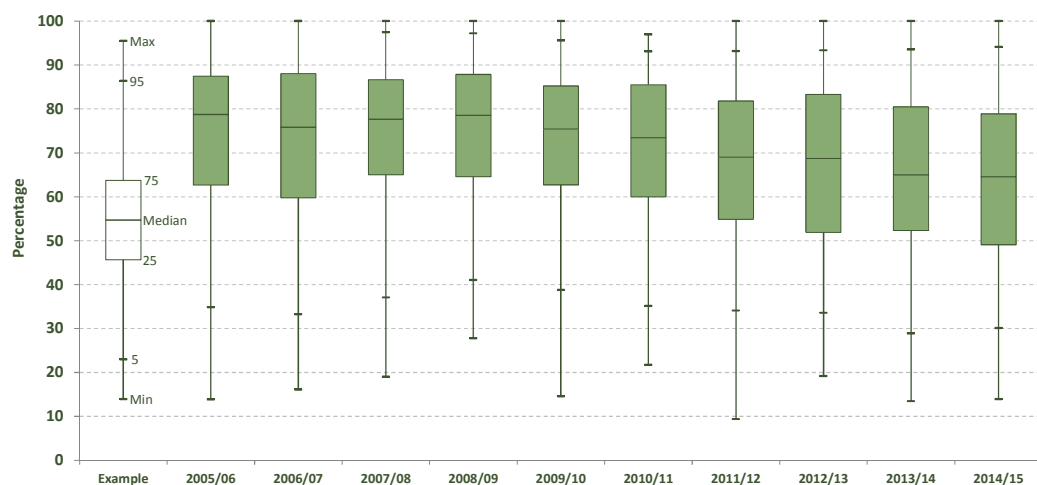
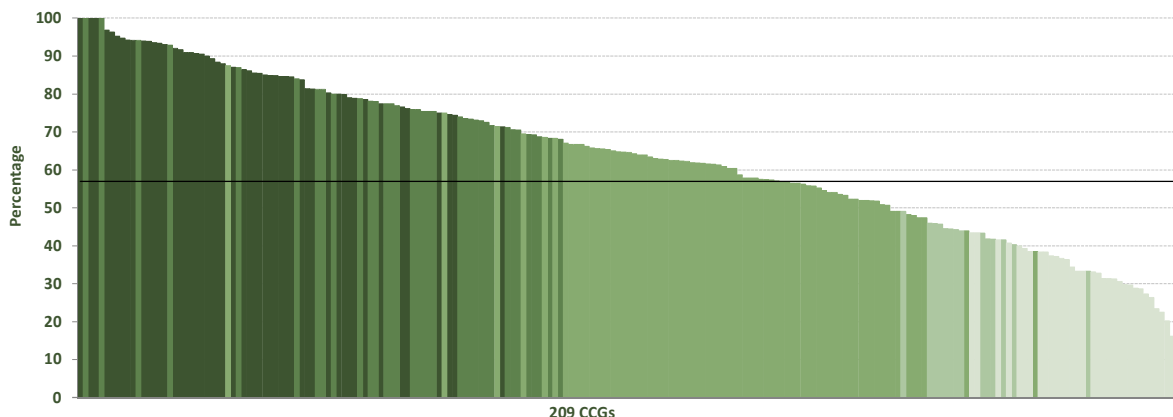
- Significantly higher than England - 99.8% level (51)
- Significantly higher than England - 95% level (35)
- Not significantly different from England (76)
- Significantly lower than England - 95% level (14)
- Significantly lower than England - 99.8% level (33)

LONDON



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Variation in percentage of admissions for paracentesis procedure that were emergency admissions by CCG (2014/15)



Max-Min (Range)		86.2	83.9	81.0	72.2	85.4	75.2	90.6	80.9	86.6	86.1	No significant change
95th-5th percentile		65.1	66.8	60.4	56.1	56.8	57.9	59.1	59.8	64.7	64.0	No significant change
75th-25th percentile		24.8	28.2	21.6	23.3	22.5	25.5	26.9	31.4	28.2	29.8	No significant change
Median		78.8	75.9	77.7	78.6	75.4	73.5	69.0	68.8	65.0	64.6	DECREASING Significant

Context

Ascites is the accumulation of fluid in the peritoneal cavity, which develops as complication of portal hypertension.

Ascites is the most common complication of cirrhosis, and is associated with a poorer prognosis and an impaired quality of life.¹

Ascites can cause a variety of symptoms including abdominal discomfort, poor appetite, shortness of breath, indigestion, nausea, and reduced mobility. Ascitic fluid can become infected (spontaneous bacterial peritonitis, SBP), which can be life-threatening unless treated with antibiotics.

To relieve the symptoms of ascites it is necessary to remove excess fluid from the abdomen. This can be done using treatment with diuretic drugs, usually spironolactone or furosemide, or by a large volume paracentesis procedure.

Large volume paracentesis involves insertion of a needle and tube into the peritoneal cavity to drain the fluid. It is a safe procedure and less than 1% of people experience a significant side-effect. Large volume paracentesis is a quick (6 hours) method of removing fluid from the abdomen and may be used when diuretic treatment:

- has caused side-effects
- has ceased to have an effect
- may take a long period of time (weeks) over which to have an effect

Patients can be managed as planned day cases but in many services they get repeatedly readmitted as

¹ Moore K.P. and Aithal G.P. Guidelines on the management of ascites in cirrhosis. GUT 2006;55;1-12; <http://dx.doi.org/10.1136/gut.2006.099580>

emergencies, often staying in hospital for several days while they have their paracentesis procedure.

Magnitude of variation

The maps and column chart display the data for 2014/15 for the percentage of admissions for paracentesis procedures that were emergency admissions to hospital, during which CCG values ranged from 13.9% to 100.0%, which is a 7.2-fold difference between CCGs. The England value for 2014/15 was 57.0%.

The boxplot shows the distribution of CCG values for the period 2005/06 to 2014/15. There was no significant change in any of the three variation measures between 2005/06 and 2014/15, however the median decreased significantly from 78.8% in 2005/06 to 64.6% in 2014/15.

Potential reasons for the degree of variation observed include differences in:

- rates of advance care planning to work with patients to plan admissions rather than wait for emergency admissions
- the configuration of local services with differing availability of staff and facilities to provide day case paracentesis

Options for action

Prevention of ascites involves good management of liver disease, including aspects of self-management:

- dietary - reducing salt intake, and changing the type and amount of food eaten and number of times a day food is eaten (snacking on small amounts)
- abstinence from alcohol

When planning service improvement or development to reduce emergency admissions for paracentesis procedures, commissioners, clinicians and service providers need:

- to review the emergency admission rate for paracentesis in the locality
- to identify opportunities for establishing day case paracentesis procedures
- to consider discussing advance care planning with those patients not suitable for transplantation

RESOURCES

- Moore K.P. and Aithal G.P. Guidelines on the management of ascites in cirrhosis. GUT 2006;55;1-12; <http://dx.doi.org/10.1136/gut.2006.099580>
- NICE. Cirrhosis in over 16s: assessment and management. NICE guideline [NG50]. July 2016. www.nice.org.uk/guidance/ng50
- NICE. NICE Interactive pathway. Cirrhosis overview. <https://pathways.nice.org.uk/pathways/cirrhosis>
- Subcutaneous implantation of a battery-powered catheter drainage system for managing recurrent and refractory ascites. Interventional procedures guidance [IPG479]. February 2014. www.nice.org.uk/guidance/ipg479

MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

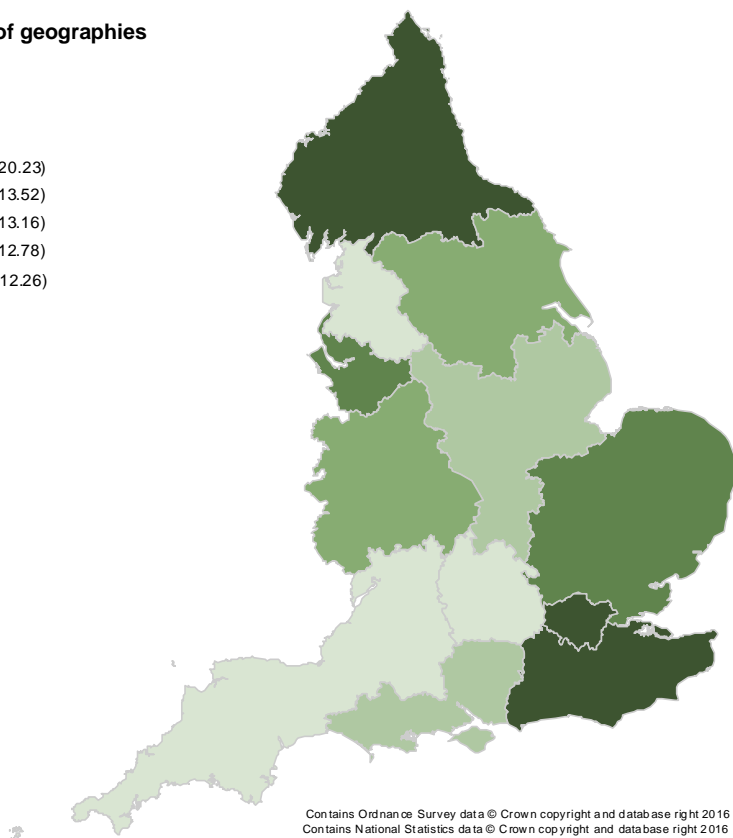
Map 27a: Variation in mean number of bed-days per liver disease patient admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)

NHS Domain 1: Preventing people from dying prematurely
 NHS Domain 4: Ensuring that people have a positive experience of care
 PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

Equal-sized quintiles of geographies

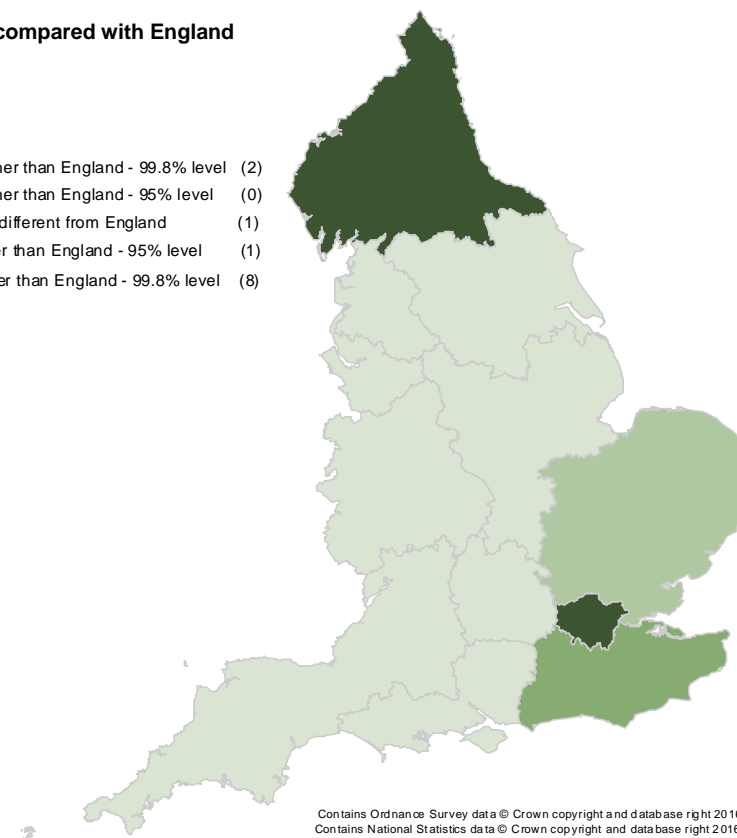
- Highest (13.53 - 20.23)
- (13.17 - 13.52)
- (12.79 - 13.16)
- (12.27 - 12.78)
- Lowest (12.07 - 12.26)



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Significance level compared with England

- Significantly higher than England - 99.8% level (2)
- Significantly higher than England - 95% level (0)
- Not significantly different from England (1)
- Significantly lower than England - 95% level (1)
- Significantly lower than England - 99.8% level (8)



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MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

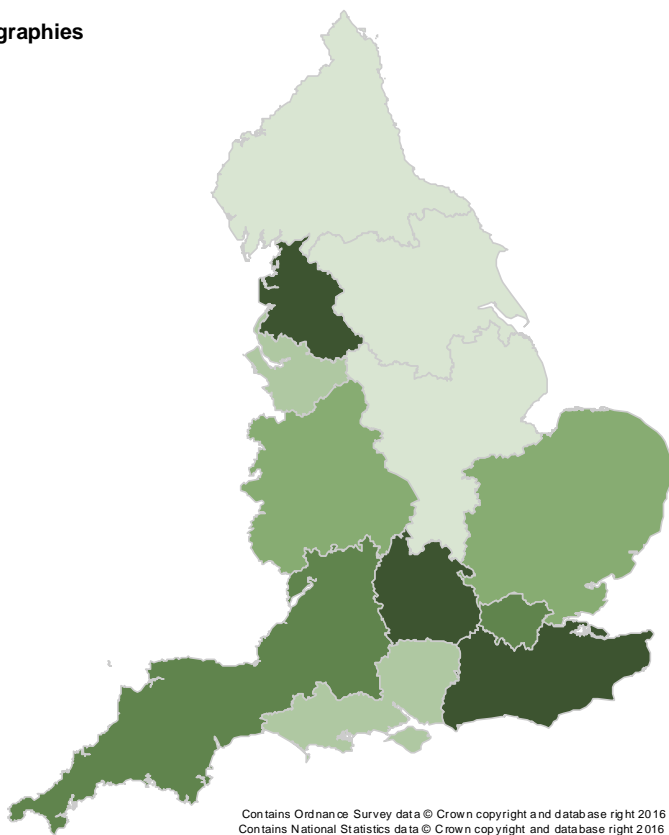
Map 27b: Variation in percentage of liver disease patients who died without being admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)

NHS Domain 1: Preventing people from dying prematurely
 NHS Domain 4: Ensuring that people have a positive experience of care
 PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: REQUIRES LOCAL INTERPRETATION

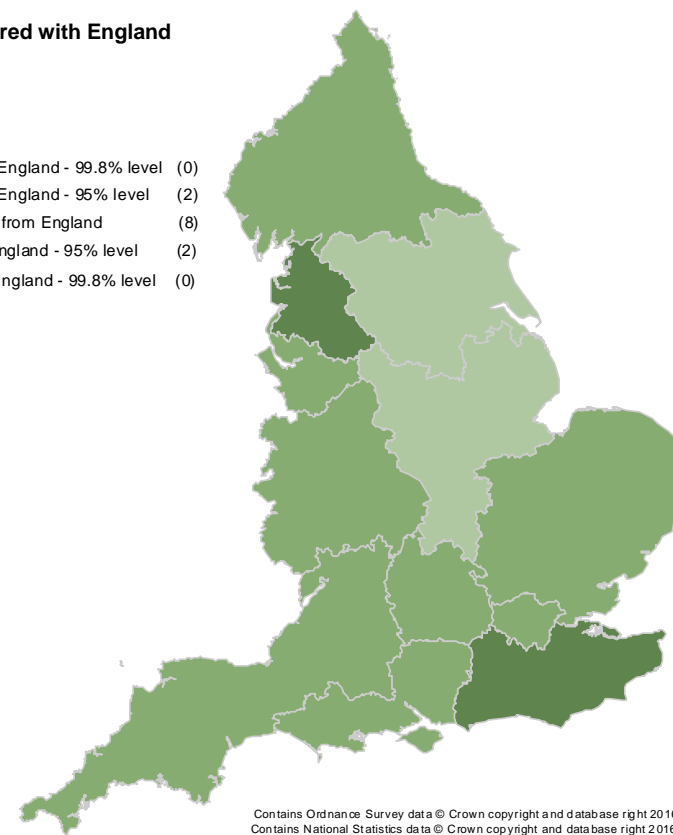
Equal-sized quintiles of geographies

- Highest (14.76 - 16.14)
- (12.90 - 14.75)
- (12.07 - 12.89)
- (11.07 - 12.06)
- Lowest (10.11 - 11.06)



Significance level compared with England

- Significantly higher than England - 99.8% level (0)
- Significantly higher than England - 95% level (2)
- Not significantly different from England (8)
- Significantly lower than England - 95% level (2)
- Significantly lower than England - 99.8% level (0)



MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

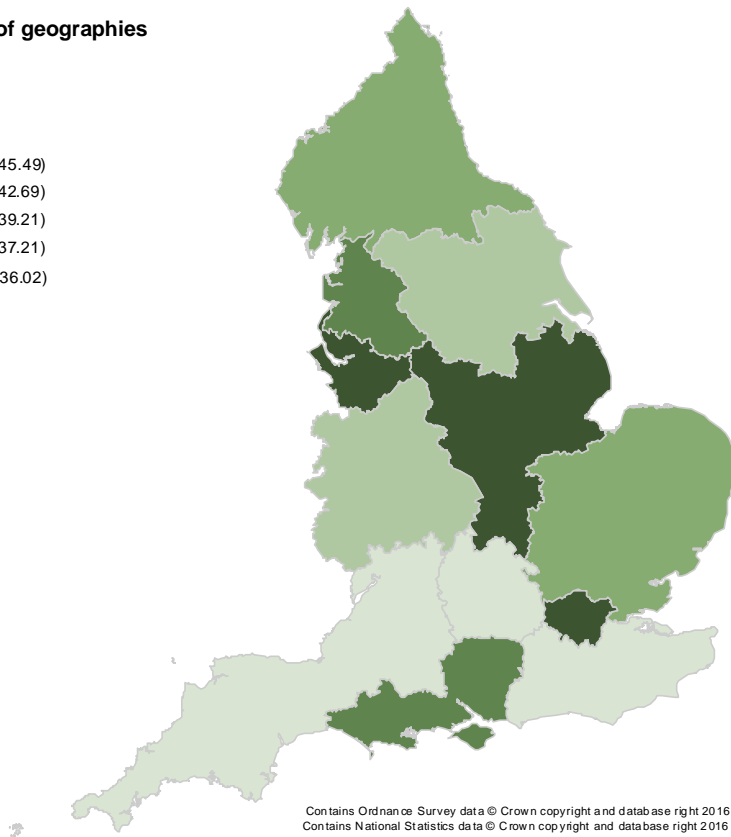
Map 27c: Variation in percentage of liver cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)

NHS Domain 4: Ensuring that people have a positive experience of care
 PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

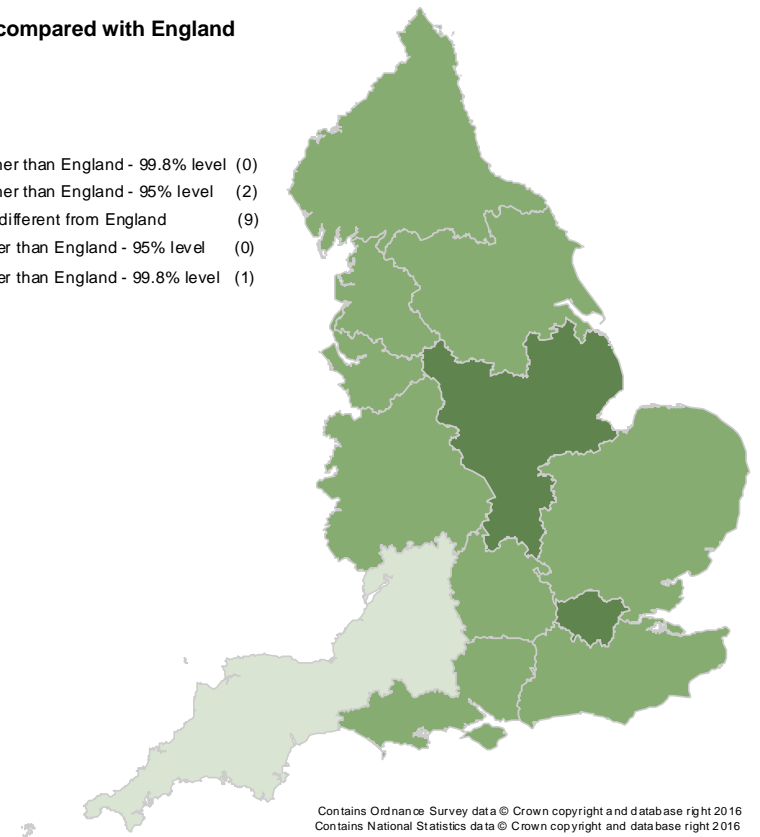
Equal-sized quintiles of geographies

- Highest (42.70 - 45.49)
- (39.22 - 42.69)
- (37.22 - 39.21)
- (36.03 - 37.21)
- Lowest (29.34 - 36.02)



Significance level compared with England

- Significantly higher than England - 99.8% level (0)
- Significantly higher than England - 95% level (2)
- Not significantly different from England (9)
- Significantly lower than England - 95% level (0)
- Significantly lower than England - 99.8% level (1)



MANAGEMENT OF COMPLICATIONS OF ADVANCED LIVER DISEASE AND END OF LIFE CARE

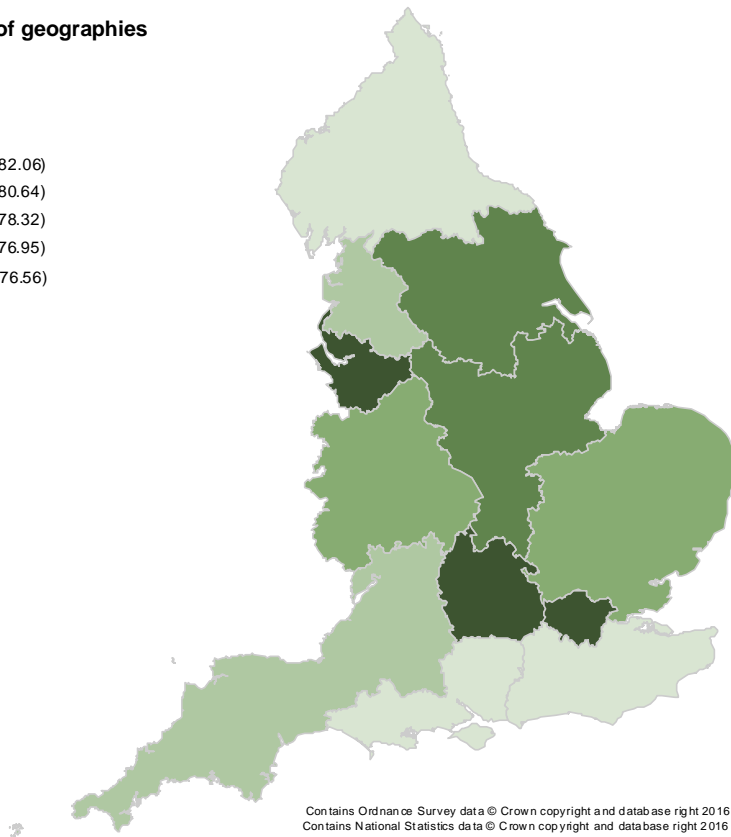
Map 27d: Variation in percentage of liver non-cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)

NHS Domain 4: Ensuring that people have a positive experience of care
 PHOF Domain 4: Healthcare public health and preventing premature mortality

OPTIMUM VALUE: LOW

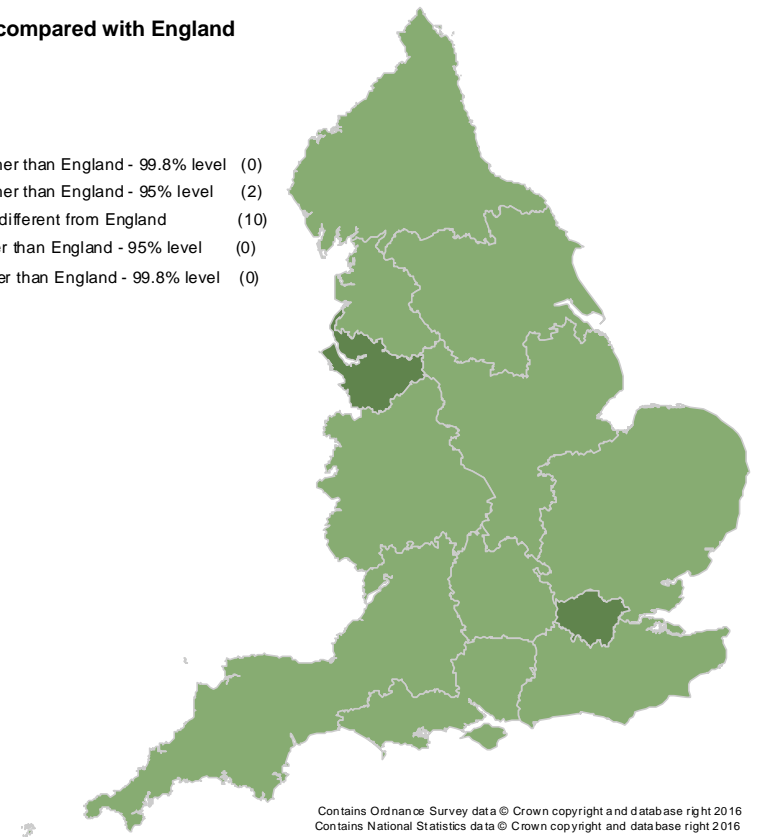
Equal-sized quintiles of geographies

- Highest (80.65 - 82.06)
- (78.33 - 80.64)
- (76.96 - 78.32)
- (76.57 - 76.95)
- Lowest (73.29 - 76.56)

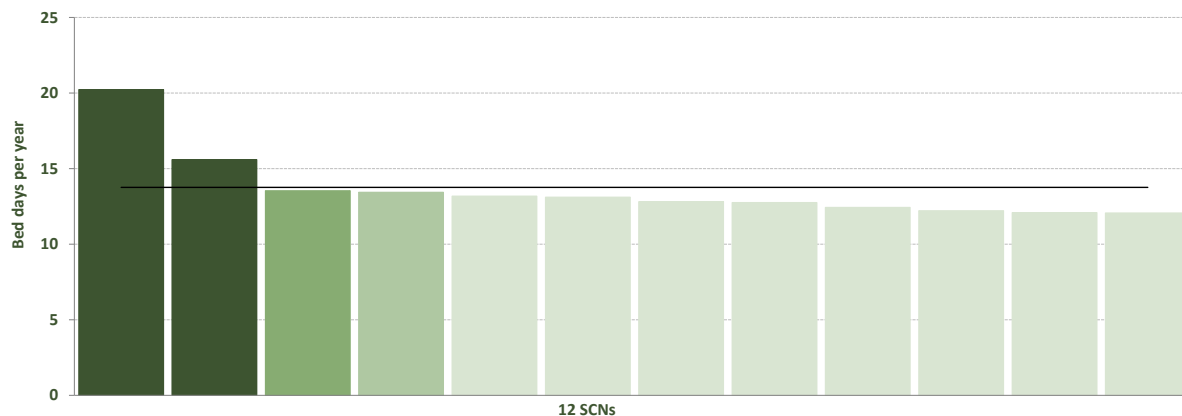


Significance level compared with England

- Significantly higher than England - 99.8% level (0)
- Significantly higher than England - 95% level (2)
- Not significantly different from England (10)
- Significantly lower than England - 95% level (0)
- Significantly lower than England - 99.8% level (0)



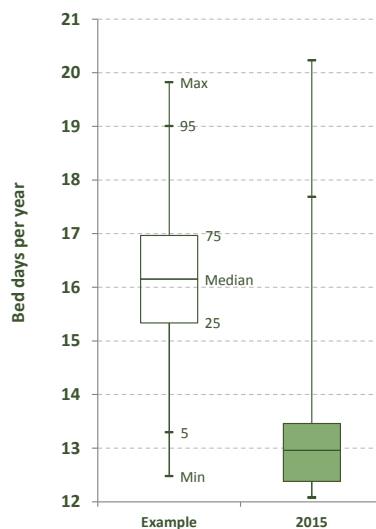
Variation in mean number of bed-days per liver disease patient admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)



Context

Liver disease is associated with an extensive illness burden towards the end-of-life. The typical clinical course is of gradual decline interspersed with episodes of acute deterioration – commonly requiring hospital admission.¹ Patients dying from end-stage liver disease suffer high levels of physical and psychological distress. Bereaved family members report poor experiences of end of life care for their loved ones and high levels of their own psychological distress.

Although a small proportion of patients with end-stage liver disease may be suitable for curative treatment through liver transplantation this option is unsuitable for the majority of patients. Patients, for whom curative options have been



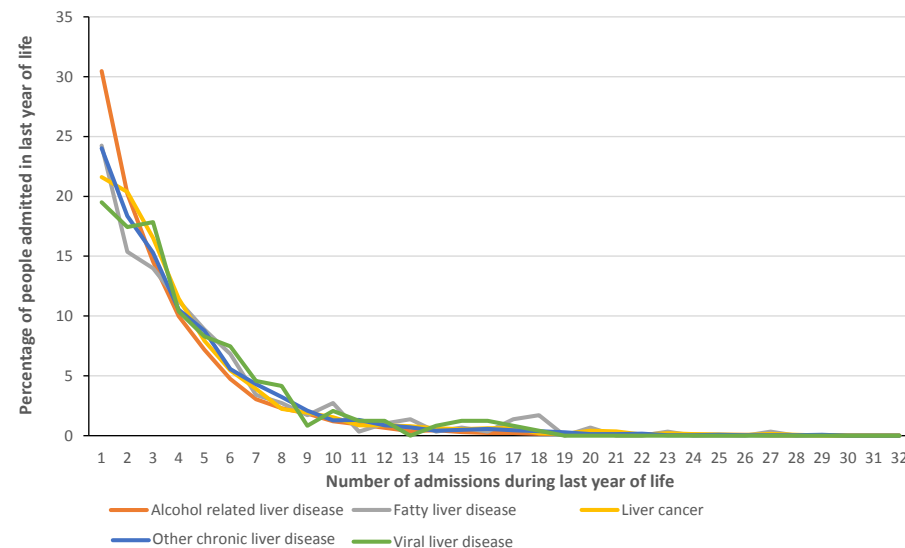
Max-Min (Range)		8.2
95th-5th percentile		5.6
75th-25th percentile		1.1
Median		13.0

exhaustive, may stand to benefit from end-of-life care planning, in particular an exploration of their choices for place of care and death once they are made aware that their condition is likely to be fatal. These choices can be recorded in an Advance Care Plan or Directive which can be shared with other health professionals.

The majority of liver disease patients (90%) are admitted into hospital in the last year of life and many have multiple admissions as illustrated in Figure 27.1 below.

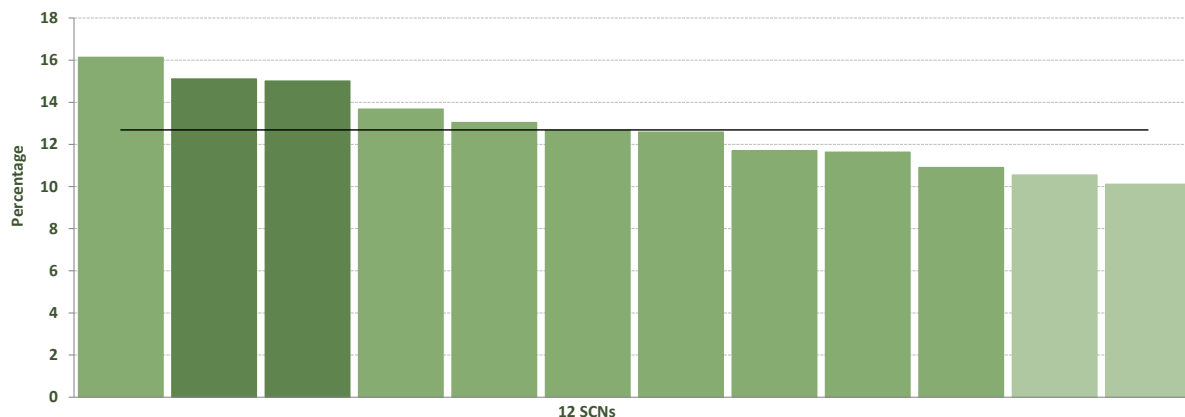
1 in 5 people who die from liver disease have five or more admissions in their last year of life.

Figure 27.1: Distribution of people who died from liver disease by number of hospital admissions in last year of life



¹ Kendrick E. Getting it right: Improving end of life care for people living with liver disease. London: Department of Health 2013.

Variation in percentage of liver disease patients who died without being admitted to hospital in the last year of life by Strategic Clinical Network (SCN) (2015)



The mean number of bed-days (Map 27a) per liver disease patient admitted to hospital in the last year of life is a proxy measure of quality. Several factors may influence the mean number of bed-days including number of admissions, severity of disease, social circumstances and support and provision of health and social care in the community. This indicator also reflects the pressure placed on acute hospital services related to the inpatient care of liver disease patients in their last year of life. It is notable because of the degree of geographical variation.

In sharp contrast, Map 27b focuses on variation in the percentage of liver disease patients who died without being admitted to hospital in the last year of life. This new indicator looks at the percentage of patients who died with liver disease recorded as

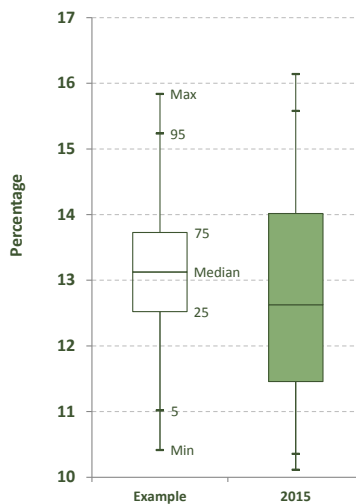
the underlying cause of death but who were not admitted to hospital in their last year of life.

It is presented by Strategic Clinical Network, as the number of patients not admitted is small. Statistically significant variations are still seen. Around 1,500 (1 in 10) people die from liver disease each year without being admitted to hospital.

Given the severity of the burden of disease experienced by people with end-stage liver disease prior to death, it could be surprising that they have not been admitted to hospital. However, it is also known that for a proportion of patients, because cirrhosis is a silent condition, their first presentation may be with a life threatening complication of decompensation.

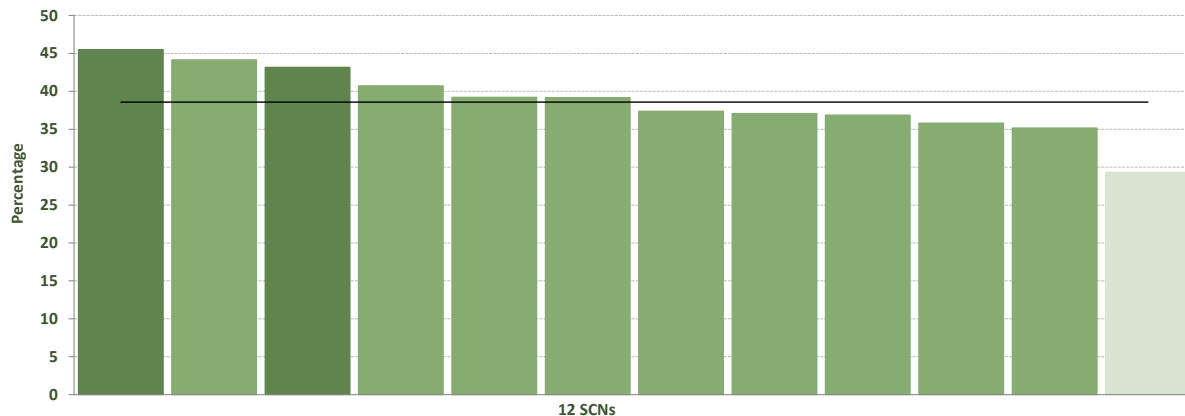
It has already been shown that there is a strong correlation between deprivation and mortality from liver disease. Many patients who die from liver disease come from particularly marginalised groups such as the homeless and those with an alcohol and/or drug dependency.

These patients often have chaotic interactions with health services and poor levels of access. The variation is important with two SCNs (Greater Manchester, Lancashire and South Cumbria, and South East Coast) having statistically higher rates than the England.



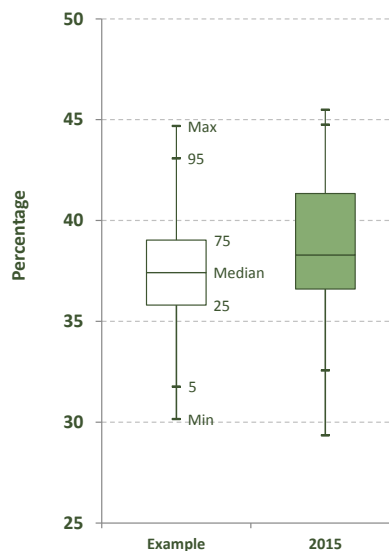
Max-Min (Range)		6.0
95th-5th percentile		5.2
75th-25th percentile		2.6
Median		12.6

Variation in percentage of liver cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)



Over two-thirds of deaths secondary to liver disease (over 80% for alcohol related liver disease – ArLD) occur in hospital.² Patients with Hepatocellular Carcinoma (HCC) are more likely to be referred to Specialist Palliative Care Services (SPCS) than those with non-cancer end-stage liver disease and therefore have a greater chance to be engaged in Advance Care Planning.

This may offer patients a greater chance of a death outside hospital, either at home or in a hospice if that is their preference. The proportion of HCC patients dying in hospital is 38.6% and among those with non-cancer liver disease, this figure is 78.0%. Maps 27c and 27d show variation in the percentage of liver cancer deaths and liver non-cancer deaths respectively which occur in hospital.



	Example	2015
Max-Min (Range)		16.2
95th-5th percentile		12.2
75th-25th percentile		4.7
Median		38.3

Magnitude of variation

Map 27a: Average number of bed days per liver disease patient admitted to hospital in the last year of life

The maps and column chart display the latest period (2015), during which SCN values ranged from 12.1 to 20.2 bed days, which is a 1.7-fold difference between SCNs. The England value for 2015 was 13.8 bed days. The boxplot shows the distribution of SCN values for the period 2015.

Map 27b: Percentage of liver disease patients who died without being admitted to hospital in the last year of life

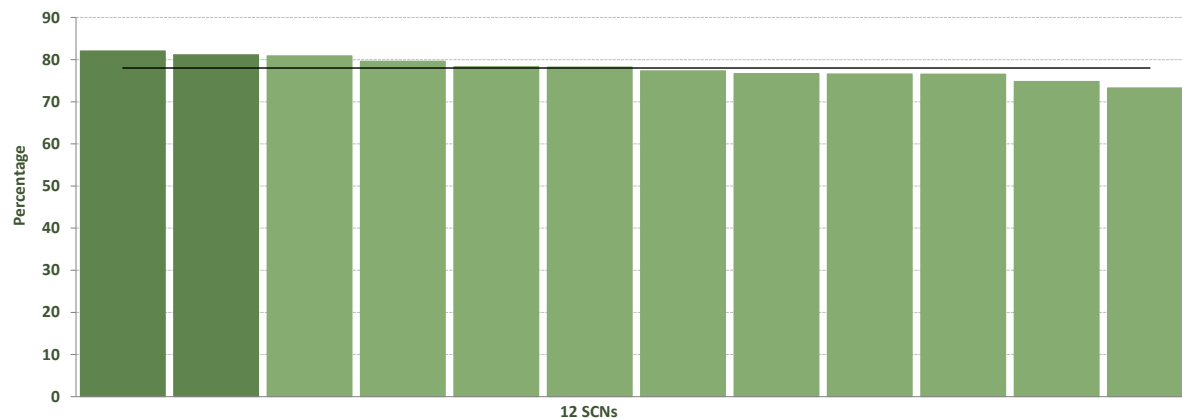
The maps and column chart display the latest period (2015), during which SCN values ranged from 10.1 to 16.1 %, which is a 1.6-fold difference between SCNs. The England value for 2015 was 12.7 %. The boxplot shows the distribution of SCN values for the period 2015.

Map 27c: Percentage of liver cancer deaths that occurred in hospital among all care facilities

The maps and column chart display the latest period (2015), during which SCN values ranged from 29.3 to 45.5 %, which is a 1.6-fold difference between SCNs. The England value for 2015 was 38.6 %. The boxplot shows the distribution of SCN values for the period 2015.

² National End of Life Care Intelligence Network. Deaths from Liver Disease: Implications for end of life care in England 2012. www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease

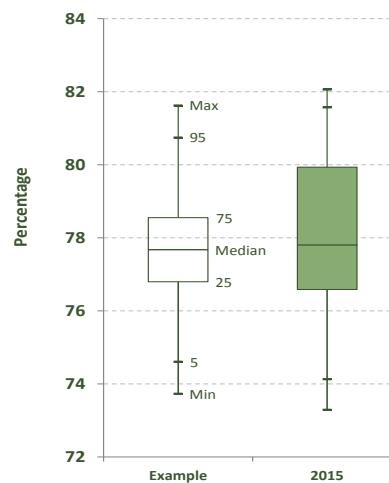
Variation in percentage of liver non-cancer deaths that occurred in hospital among all care facilities by Strategic Clinical Network (SCN) (2015)



Map 27d: Percentage of liver non-cancer deaths that occurred in hospital among all care facilities

The maps and column chart display the latest period (2015), during which SCN values ranged from 73.3 to 82.1 %, which is a 1.1-fold difference between SCNs. The England value for 2015 was 78.0 %.

The boxplot shows the distribution of SCN values for the period 2015.



	Example	2015
Max-Min (Range)		8.8
95th-5th percentile		7.4
75th-25th percentile		3.4
Median		77.8

Options for action

- Improve early detection of cirrhosis to reduce the risk of patients presenting for the first time with late stage irreversible liver disease or for the first time with life threatening complications and so that their disease can be managed proactively and for some patients even reversed
- Ensure that local trusts have appropriate policies in place to reduce preventable deaths in patients with liver disease. These were highlighted in two NCEPOD Reports.^{3,4} This will include the timely recognition of patients with the complications of advanced liver disease in A&E⁵ and appropriate management of patients presenting with alcohol related liver disease and upper gastrointestinal bleeding.^{3,4} Variceal bleeding and ascites can also be managed proactively with appropriate planning and patient involvement (see maps 25 and 26)
- Review average number of bed days in last year of life for patients dying from liver disease
- Review the number of people who die from liver disease without an admission in the last year of life and the circumstances surrounding this perhaps through local audit
- Review the proportion of liver disease patients who die in hospital in the local area from cancer and non-cancer related liver disease
- Review local policies for end-stage liver disease patients in relation to national guidance for end of life

³ National Confidential Enquiry into Patient Outcome and Death. Alcohol Related Liver Disease: Measuring the Units. 2013. www.ncepod.org.uk/2013arld.html

⁴ National Confidential Enquiry into Patient Outcome and Death. Gastrointestinal Haemorrhage: Time to Get Control? 2015. <http://www.ncepod.org.uk/2015gih.html>

⁵ BSG - BASL Decompensated Cirrhosis Care Bundle - First 24 Hours <http://www.bsg.org.uk/care-bundles/care-bundles-general/decompensated-cirrhosis-care-bundle-first-24-hours.html>

care for liver disease patients,¹ national policy and NICE Guidance

- Work with local charities and statutory bodies working with vulnerable groups with high risk of liver disease to ensure good access to health services and good end of life care

RESOURCES

- Kendrick E. Getting it right: Improving end of life care for people living with liver disease. London: Department of Health 2013.
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- BSG - BASL Decompensated Cirrhosis Care Bundle - First 24 Hours www.bsg.org.uk/care-bundles/care-bundles-general/decompensated-cirrhosis-care-bundle-first-24-hours.html
- The Choice in End of Life Care Programme Board. What's important to me. A Review of Choice in End of Life Care. 2015. www.gov.uk/government/publications/choice-in-end-of-life-care
- National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. 2015. <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>
- NICE End of life care for adults. Quality standard [QS13] November 2011. www.nice.org.uk/guidance/qs13
- NICE Care of dying adults in the last days of life. Quality standard [QS144] March 2017. www.nice.org.uk/guidance/qs144
- Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015. April 2016. www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015