

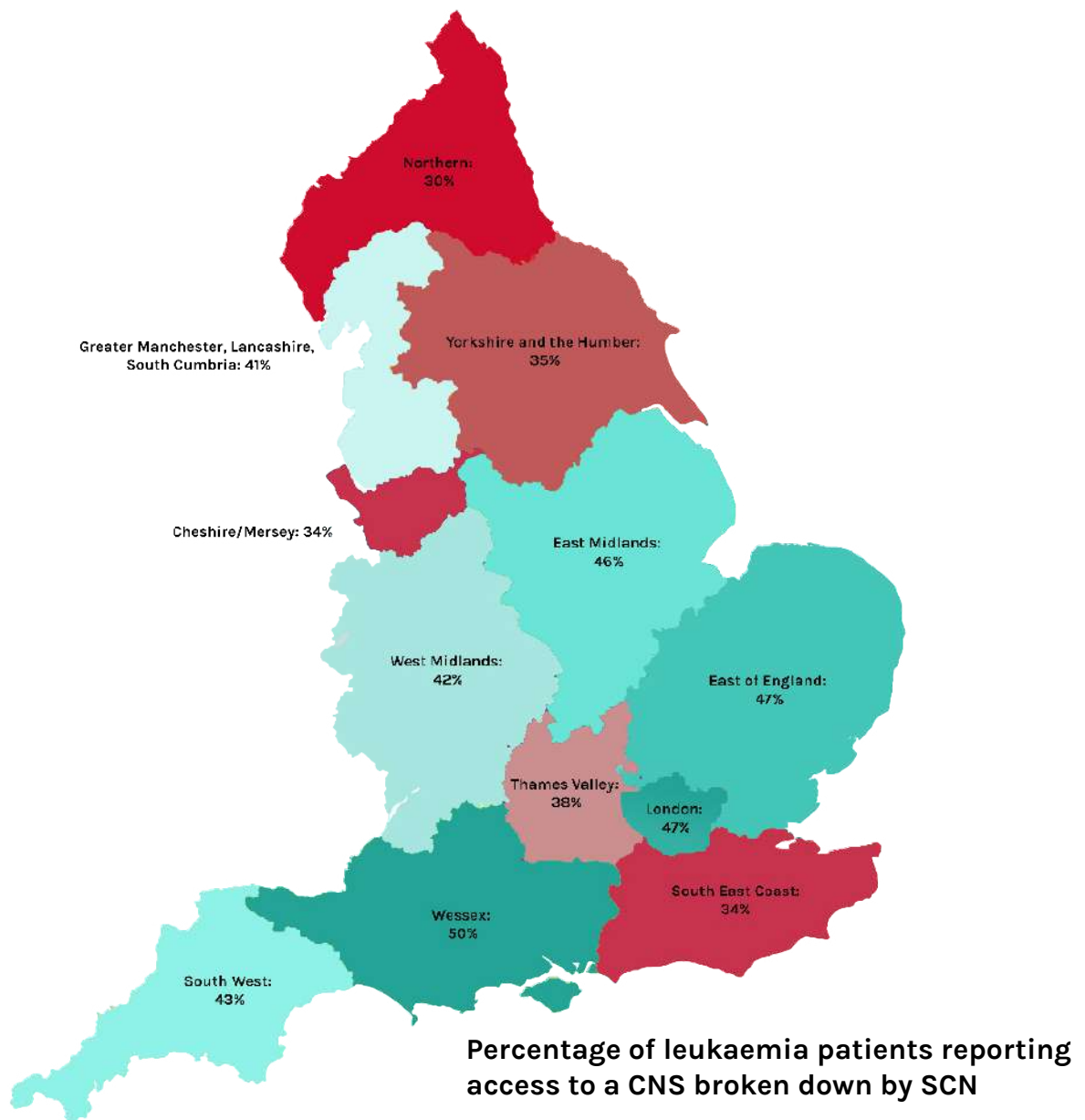
# Leukaemia Care

YOUR Blood Cancer Charity

## My CNS Matters:

### The invaluable role of a Clinical Nurse Specialist (CNS)

Demonstrating the value that Clinical Nurse Specialists add to leukaemia patient experience and highlighting issues with access





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**Abbreviations:**

CNS: Clinical Nurse Specialist  
 CPES: Cancer Patient Experience Survey  
 MDT: Multi-disciplinary Team  
 WTE: Working Time Equivalent  
 SCN: Strategic Clinical Networks  
 ALL: Acute Lymphoblastic Leukaemia  
 AML: Acute Myeloid Leukaemia  
 CML: Chronic Myeloid Leukaemia  
 CLL: Chronic Lymphocytic Leukaemia

## Executive Summary

In 2015 NHS England set the target that by 2020 all cancer patients should have access to a Clinical Nurse Specialist (CNS), or other named key-worker. While the National Cancer Patient Experience Survey (CPES) from 2015 suggested that 85% of leukaemia patients had 'been given the name of a CNS', findings from the Leukaemia Care 2016 patient experience survey suggest that CNS access is actually much poorer.

But why does CNS access matter? As one patient expressed it - *"The CNS was invaluable."*

### Value added to the NHS

By identifying the key roles of a CNS, the Royal College of Nursing has been able to evidence the huge cost savings and efficiency improvements that Clinical Nurse Specialists bring to the NHS.

### Value added to patient experience

Beyond monetary value, there is also significant evidence to show how CNS access improves the experience of patients. Included within this is the CPES survey, which identified CNS access as the most positive influencing factor in patient experience.

Following just 38% of leukaemia patients stating they had CNS access in the Leukaemia Care 2016 patient experience survey, we wanted to identify exactly how access to a CNS improves the experience of leukaemia patients and whether there were any particular issues affecting access.

We did this in two ways:

- 1) We divided responses to our survey from the 2019 leukaemia patients, by those who said they had access to a CNS and those who did not. This enabled us to uncover the impact that CNS access had from diagnosis through to living with or beyond leukaemia.
- 2) We sent out 210 Freedom of Information Requests to hospital trusts to understand CNS availability across regions within England, the extent of specialisation of Clinical Nurse Specialists, and assess whether NHS burden or lack of training could be impacting CNS numbers and hence access.

### What did we find?

#### Value added to patient experience

66% of patients without CNS access were also not offered any additional support, despite the majority wanting it.

Patients without a CNS are more likely to not understand the reasons for being placed on the 'watch and wait' scheme, more likely to feel concerned and twice as likely to not receive any

supportive written information.

Nearly all patients with a CNS felt involved in decisions about their treatment to some extent, whereas 1 in 10 patients without a CNS did not feel involved at all.

1 in 5 of the patients without a CNS was left either without an explanation of their results or not understanding the one that was given.

Patients with a CNS were more likely to receive both verbal and written information about support groups; receive advice about finding further information; and more likely to be directed to trusted websites.

## **CNS Access**

Patients without CNS access are more likely to reach out to charities for support.

Leukaemia patients in England are more likely to have access to a CNS compared to Wales and Scotland.

The regional variations across the UK are between 30% and 50% of patients having access to a CNS.

CNS numbers have increased between 2015 and 2017, but approximately only 25% of trusts have a leukaemia specific clinical nurse specialist.

Shortages in the nursing workforce across the NHS have an impact on the availability of clinical nurse specialists, particularly at busy periods (e.g. the winter).

## **Our Recommendations**

- 1) Ensuring that patients are introduced to their CNS from diagnosis.**
- 2) Increasing the specialisation of Clinical Nurse Specialists for leukaemias.**
- 3) A general improvement in nursing staff levels across the NHS so that clinical nurse specialists no longer have to cover the shifts of general nurses.**

## THE INVALUABLE ROLE OF A CLINICAL NURSE SPECIALIST (CNS)

Each year over 9,000 people are diagnosed with a leukaemia in the UK and a diagnosis can have a huge emotional, physical and practical impact on patients and their families. To ensure that patient's needs are supported; in 2015 NHS England set the objective that "all patients receive patient centred care with respect and dignity which takes account of their holistic needs"<sup>i</sup>.

To fulfil this objective the concept of a 'key worker' was introduced – a named healthcare professional who is responsible for each individual patient's needs. In many hospitals, a patient's key worker will be a Clinical Nurse Specialist (CNS).

### Who are clinical nurse specialists?

There is no single definition of a CNS – but generally a CNS will be educated to a postgraduate degree level and/or have significant experience in managing and caring for a particular disease type or patient group. To be able to deal with patients at any stage on their cancer pathway, the CNS will have a detailed understanding of the physical and psychological effects, and be responsible for having, and providing, up-to-date training within their area of expertise<sup>ii</sup>.

Leukaemia patients may have interactions with Clinical Nurse Specialists who cover general haematological disorders, specific blood cancers, clinical trials, stem cell transplants or palliative care.

### What are clinical nurse specialists responsible for?

#### **1) Emotional and Practical Support for Patients**

From diagnosis, a CNS supports patients and their families at nurse-led clinics and over the phone. The CNS uses a holistic approach to assess the physical and psychological needs of each patient in order to encompass all the care needs identified. They provide both verbal and written information relating to treatments, managing side effects and practical guidance on living with cancer.

#### **2) Co-ordination of Patient Care**

At the centre of each patient's care, the CNS is a valuable part of the multi-disciplinary team (MDT) – a team of healthcare workers from different disciplines that are involved in the patient's care. The CNS is vital for ensuring that there is communication between each member of the patient's care team. A CNS is also responsible for arranging appointments and hospital admissions – making necessary adjustments for emergencies.

#### **3) Delivery of Patient Care**

Equipping patients for at home recoveries, running follow-up clinics and in some cases, having the experience to administer treatments such as chemotherapy. The CNS is invaluable for delivering patient care.

#### **4) Educating Healthcare Professionals**

A crucial part of the CNS role is to act as a mentor and ensure that other members of the team are educated and up-to-date on developments within their area of expertise. An important part of this is teaching of junior nurses in the knowledge and skill of haematology in order for them to care for this patient group.

#### **5) Patient Advocate**

A CNS is required to act on behalf of the patients to ensure good patient experience and outcomes. This includes: acting on behalf of the patient at MDT meetings, identifying and implementing service improvement and efficiencies, and challenging decisions if needed.

### **Who should have access to a CNS?**

According to the National Cancer Patient Experience Survey (CPES), CNS support is the biggest factor contributing to a positive patient experience. The five-year Cancer Strategy therefore recommends that "all patients have access to a CNS or other key worker from diagnosis onwards"<sup>iii</sup>.

### **Are there other titles for a CNS?**

Around 78% of cancer nurse specialists have the title of a Clinical Nurse Specialist, however, there are other titles, including Advanced Nurse Practitioner, Nurse Practitioner and Specialist Nurse. If training of a CNS has been funded by Macmillan, the CNS retains the title of a Macmillan Nurse.

Unfortunately, the differing titles of a cancer nurse specialist leads to a lack of understanding on the responsibility of each nurse for both patients and healthcare teams too. This is perhaps reflective of the lack of structured framework in the UK relating to required training and role definitions.



## THE INVALUABLE ROLE OF A CNS – VALUE ADDED TO THE NHS

Before taking a look at how CNS access affects the experience of leukaemia patients, it's worthwhile considering the value that Clinical Nurse Specialists add to the NHS. Ultimately, there is much evidence to suggest that the cost of a CNS is an efficient and cost-effective use of NHS resources.

### How are clinical nurse specialists valuable for the NHS?

A CNS can provide better quality, more efficient care at a reduced cost. This is how<sup>iv</sup>:

#### 1) Ensuring consultant and hospital time is used efficiently

A CNS can assess whether patients require outpatient appointments, freeing up consultant time. Ongoing management of the patient's condition can ensure that emerging health issues are identified earlier, avoiding hospitalisation. Equipping patients and their families for at home recovery can also reduce the length of hospital stays.

#### 2) Fulfilling roles that would otherwise be done at a more expensive cost

In most hospitals there will be nurse-led clinics where the CNS sees follow-up patients. This not only frees up consultants to see new patients, but the cost of running a CNS clinic is much less than a consultant led clinic.

#### 3) Maximising efficiency through innovative ideas

Identifying both new technologies and ways to maximise the available resources is a crucial part of the CNS management role. They are therefore at the centre of improving the efficiency of processes and staffing systems in a patient focused manner.

### What is the estimated saving of a CNS?

An estimated average salary for a CNS is £37,467 per year<sup>v</sup>. A study done on the work of rheumatology Clinical Nurse Specialists by the Royal College of Nursing suggested that the work carried out by a CNS is the equivalent of £72,128 per year. Additional savings include £175,168 per year in freeing up consultant appointments and £72,588 in GP appointments<sup>vi</sup>.

### Is the value of clinical nurse specialists recognised in the NHS?

The value of a specialist nursing role was recognised during the 1980/90s and the number of Clinical Nurse Specialists increased. Over time, however, NHS trusts began to reduce CNS numbers as a cost-cutting measure. This may be in part due to the lack of clarity in the differing roles of specialist nurses, which made it hard to produce an effective business case for the value of a CNS<sup>vii</sup>.

In recent years, however, numbers of Clinical Nurse Specialists have increased, following a

number of studies demonstrating the cost-effectiveness of the CNS role and the value added to patient experience. Macmillan's most recent specialist nursing consensus revealed an increase in numbers from 2,260 working time equivalent (WTE)\* in 2011 to 2,745 WTE in 2014. This represents a 21% increase across 3 years.

Since this consensus the Independent Cancer Taskforce Five Year Strategy was published (2015) that again recognised the value of a CNS in patient care and set the agenda for all patients to have access. The issue is that cancer incidence is increasing by 3.2% every year, meaning that CNS numbers also need to be increasing to manage the extra workload.

\*working time equivalent (WTE) is equal to the accumulative number of hours worked by all Clinical Nurse Specialists divided by 37.5 (the equivalent of one full-time nurse) i.e. 1 WTE = 37.5 hours CNS work.

## THE INVALUABLE ROLE OF CNS – VALUE ADDED TO PATIENT EXPERIENCE

It is clear from the role of a CNS in supporting and advocating for patients, that they play a crucial role in ensuring patients receive the most efficient and best possible care. It is, therefore, no wonder why access to a CNS is the most positive influencing factor in cancer patient experience. Here we use our 2016 patient experience survey to reveal quantifiable evidence of the benefit a CNS adds to leukaemia patient experience.

### The Leukaemia Care 2016 Patient Experience Survey

Between September and December 2016 Leukaemia Care carried out a blood cancer patient experience survey in partnership with Quality Health. The survey was designed to gather a full picture of patient experience from before diagnosis through to living with, or beyond, cancer.

The survey was sent to two distinct cohorts of patients over the age of 16 years old:

**Arm 1: A paper survey of leukaemia patients who had previously responded to the National Cancer Patient Experience Survey (CPES) and agreed to be contacted again.**

**Arm 2: An anonymous online survey of the wider blood cancer community, distributed by various charity and patient advocate channels.**

### Survey responses

For the purpose of this report the leukaemia patient respondents from both cohorts have been combined to assess the impact of CNS access on all leukaemia patients. This means that there are a total of 2019 respondents.

	CML	CLL	ALL	AML	Other	Total
Number of Respondents	292	1007	151	373	206	2019*

\*Patients were able to select multiple options for leukaemia type, which is why the total number of respondents is lower than all leukaemia types added together (2029).

The numbers of respondents from each leukaemia type are reflective of the overall national demographics, with CLL being the most common adulthood leukaemia and ALL being the least prevalent leukaemia in adults.

### Overall access to a CNS

In the National CPES survey, 85% of leukaemia patients stated that they had been given the name of a CNS<sup>viii</sup>.

Question 49 of the Leukaemia Care survey asked, 'were you offered additional support in any of the following areas?'

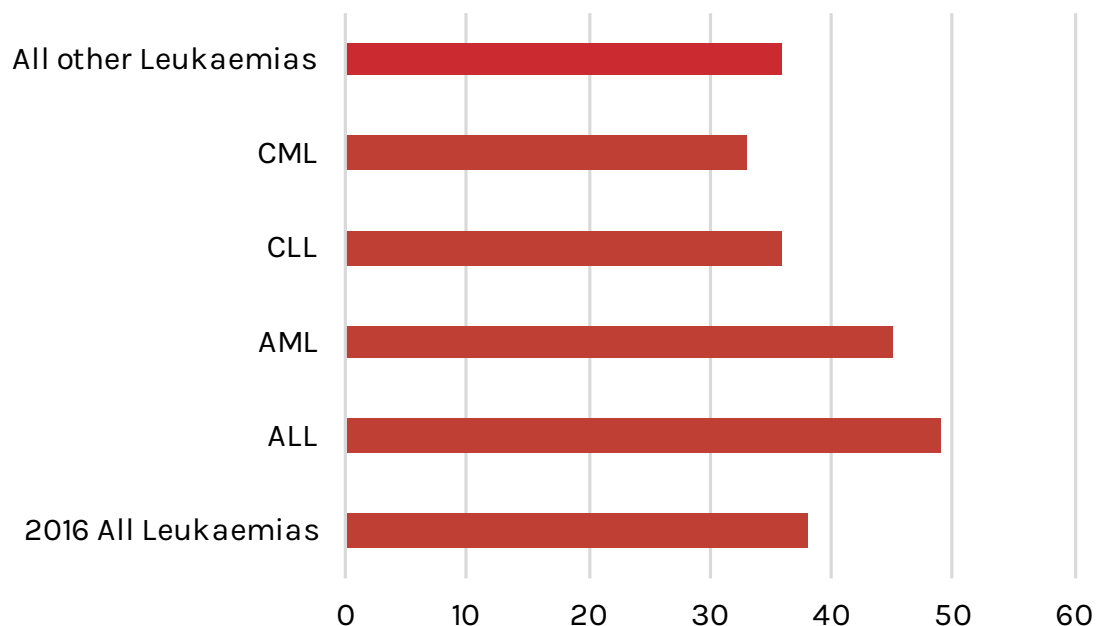
Additional support areas included:

- Buddying or befriending
- Counselling or psychotherapy
- Access to a Clinical Nurse Specialist (CNS)
- Support groups
- Other
- I was not offered additional support

Our findings reveal surprisingly low levels of access to a CNS, with just 38% of all leukaemia patients saying that they were offered access to a CNS.

Significantly different levels of access were identified across leukaemia types also. Around 46% of acute leukaemia patients were offered access to a CNS, whereas this figure was just 35% for chronic leukaemia patients. This is reflective of wider findings on overall lack of support offered for chronic leukaemia patients.

[The percentage of patients with access to a CNS by leukaemia type:](#)



## **At diagnosis**

It is widely accepted that many people have heard of the word leukaemia, but understanding of what the word actually means is relatively poor. In the survey we identified that 68% of patients did not know anything about leukaemia at diagnosis, regardless of whether they had heard of leukaemia before or not.

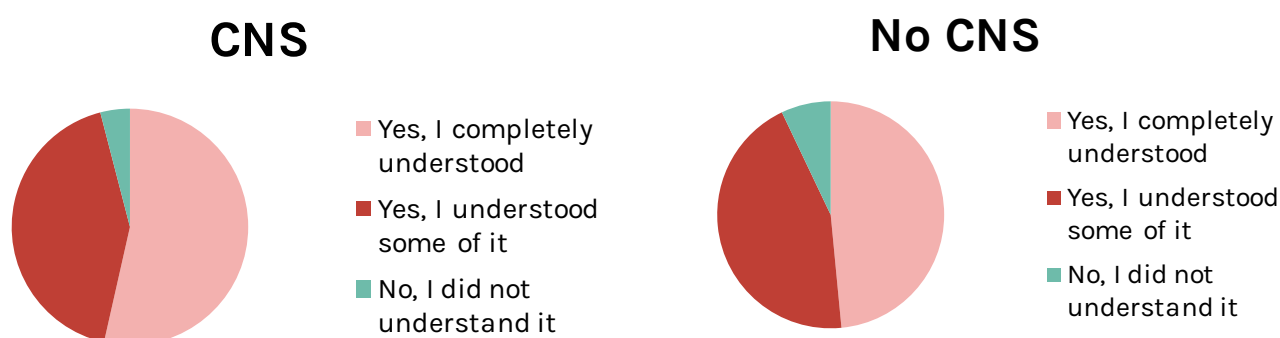
This highlights how important it is that patients are given a full and understandable explanation of their type of leukaemia at diagnosis. In many hospitals a CNS will be present at this initial appointment.

## At diagnosis: understanding

Only half (50%) of all leukaemia patients completely understood the explanation at diagnosis. However, this was more likely if a patient had access to a CNS, with 53% stating that they completely understood the explanation compared to just 48% of those without a CNS.

Similarly, patients without access to a CNS were more likely to state they did not understand the explanation at all, 7% of patients compared to just 4% of those with a CNS.

### Patient's level of understanding of their diagnosis when explained:



## At diagnosis: finding out about prognosis

One of the first things patients report thinking at diagnosis are questions about how the cancer will affect them and questions about their survival.

*"And then I started asking the questions like 'am I going to die?'" [CML patient, diagnosed 32 years old]*

80% of all patients were told about their prognosis and survival chances at diagnosis. It was, however, far more likely for patients without a CNS to not be told anything (22%) compared to those who had access to a CNS (15%).

## Treatment and care

Most respondents (58%) reported starting treatment immediately after diagnosis, as opposed to being placed on 'watch and wait' (42%). This is a regime of monitoring the progress of the cancer and only treating when necessary.

The distribution of patient access to a CNS did not differ significantly between 'watch and wait'

and starting treatment. In other words, there was no difference in access to a CNS depending on whether patients started treatment straight away or were placed on 'watch and wait'.

	Offered Access to CNS	Not Offered Access to a CNS	TOTAL
Start Treatment	449 (39%)	696 (61%)	1145
'Watch and Wait'	307 (37%)	523 (63%)	830

## **Treatment and care: 'watch and wait'**

Generally, acute leukaemia patients and CML patients will start treatment relatively quickly after diagnosis. This is why over 90% of the patients on 'watch and wait' have a CLL diagnosis. As you can see above just 37% of 'watch and wait' patients had access to a CNS. This may be due to patients being seen as a follow-up at their GP, rather than at the hospital where there are major implications for the experience of patients who do not have access.

## **Understanding of 'watch and wait'**

1) Patients without access to a CNS are six-times more likely to not understand the reasons for being placed on 'watch and wait'.

## **Emotional impact of 'watch and wait'**

1) Patients with access to CNS were far less likely to report being 'very worried' about 'watch and wait' (9%) compared to those without a CNS (14%) and far more likely to report having no concerns (50% vs. 43%, respectively).

## **Provision of written information on 'watch and wait' for those who wanted it**

1) Patients with a CNS are twice as likely to be provided with supportive, written information on 'watch and wait' compared to those without a CNS. 78% compared to just 40%, respectively.

2) Of those who were provided written information, general understanding was very good with approximately 87% of patients reporting it easy to understand. The proportion of patients reporting this was, however, greater in those with access to a CNS (89%) than patients without a CNS (79%).

## Treatment and care: clinical trials

We have previously identified issues with patients being offered the choice of a clinical trial and identified that only half of patients were given the option of participating, with significant differences between leukaemia types and age groups. We were interested to see if CNS access impacted this too.

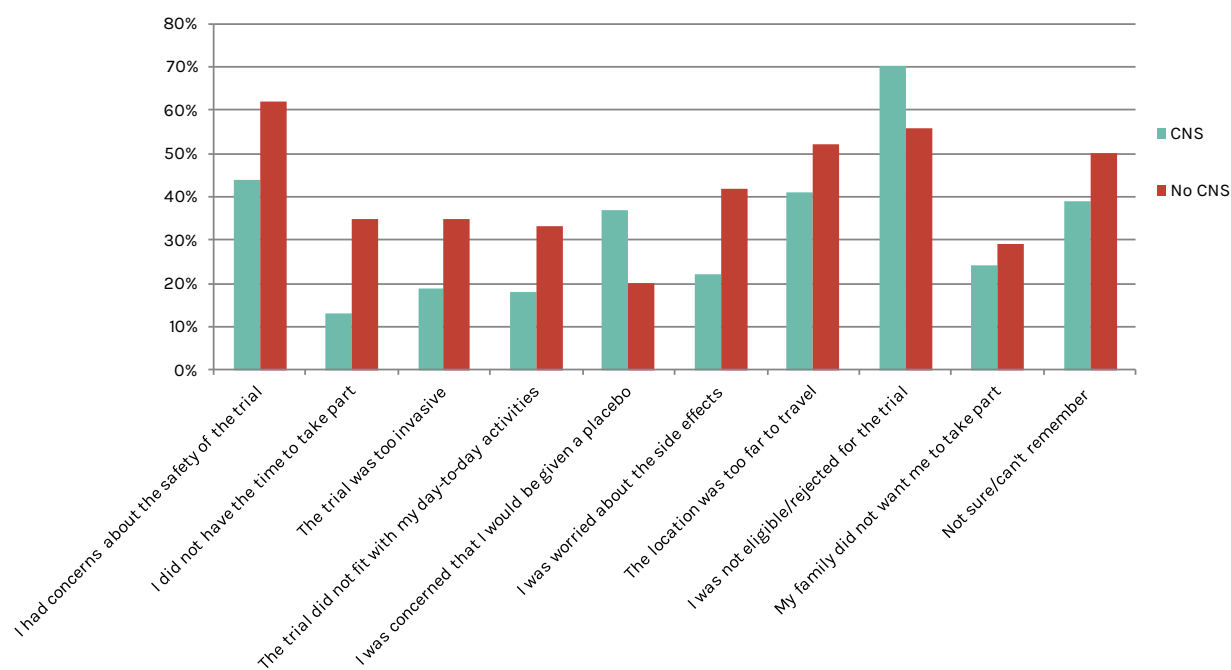
It was identified that 55% of patients with a CNS were given the option of participating in a clinical trial compared to just 47% of patients without. Most significantly, those with a CNS were, also, more likely to join a trial.

Of those patients who didn't join a clinical trial, the major reason for those without a CNS was 'concerns over the safety of the trial' indicated by 62% of patients. For those patients with a CNS, far fewer had this concern (44%) and by far the biggest reason for patients not joining was because they were ineligible/rejected (70% of respondents).

These findings may be a promising indication that the majority of patients entering clinical trials are given CNS access, perhaps more specifically a CNS specialised in clinical trials.

Whether this is the case or not, the findings clearly demonstrate that having access to a CNS can help patients to better understand clinical trials and have fewer concerns when joining.

### The reasons that patients did not join a clinical trial:



## Treatment and care: involvement in care

We asked patients whether they were involved in decisions about their treatment and care as much as they would have liked. Overall figures were positive with 72% responding 'yes, definitely', 21% 'to some extent' and just '6%' saying no.

Those with access to a CNS were much more positive in their responses, with 77% stating 'yes definitely' compared to 70% of those without CNS access.

Overall, nearly all patients with a CNS felt as though they were involved in their care as much as they wanted to be, at least to some extent. Whereas for those without a CNS, almost 1 in 10 patients felt they were not involved in decisions at all.

One of the contributing factors to responses on this question may be relating to whether patients were offered choices of treatments, which was more likely to happen for patients who had CNS access compared to those who did not (34% vs. 29% respectively).

## **After treatment**

Patients with access to a CNS were slightly more likely to have relapsed compared to those without CNS access. However, of the patients who had relapsed, the proportion of patients who had relapsed 3 or more times was greater without CNS access (24%) compared to with CNS access (17%).

These findings may be indicative that patients are being offered a CNS at the point of stem cell transplant.

Additionally, patients with a CNS were almost twice as likely to have had a stem cell transplant compared to those without (22% vs 12%).

The figures could also be demonstrable of the differing CNS access between acute and chronic leukaemia types, as relapsing 3 or more times would likely be a chronic leukaemia diagnosis and the majority of those who have had stem cell transplants will be acute patients.

## **Testing and monitoring**

Nearly all (97%) leukaemia patients who responded to the survey were still undergoing regular testing or monitoring. This did not impact the access to a CNS, nor did the time between testing/monitoring visits differ significantly between patients with, or without, CNS access.

However, patients with a CNS were more likely to say they completely understood the explanation of their results. Almost 1 in 5 of patients without a CNS are left without an explanation, or not understanding the explanation that is given.

## **Support for people with blood cancers**

A diagnosis of a blood cancer can have huge impacts on the lives of patients, in terms of emotional and physical wellbeing, and their ability to work, perform daily routines and live independently. The provision of a CNS does not alter the affect a leukaemia diagnosis has on lives of patients, but does significantly alter the level of support that a patient receives.



## **Provision of information**

Of the patients who wished to receive extra information of support or self-help groups, 88% of those with a CNS did but only 70% of those without a CNS received any information.

The format in which this information was received also differed. 71% of patients with a CNS received both verbal and written information, whereas only 62% of those without a CNS received both.

Interestingly, understanding of the information did not differ with 66% of patients reporting "it was easy to understand and I understood all of it".

## **Finding further information**

Patients without a CNS were almost twice as likely not to be offered any additional advice about finding further information (36% compared to 20% with a CNS).

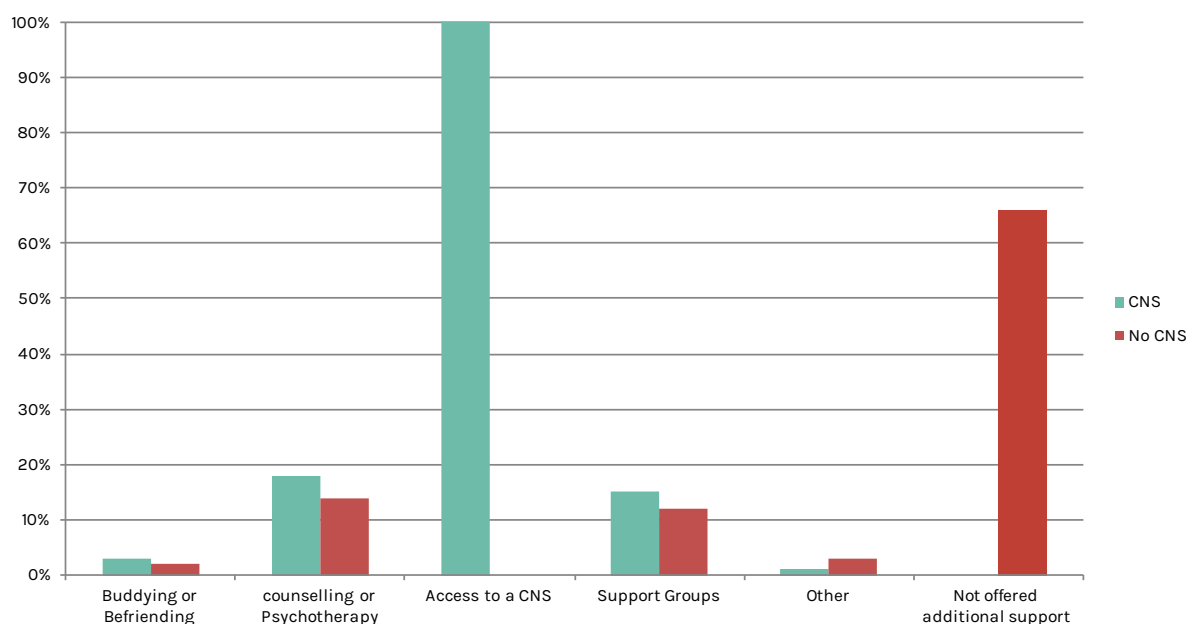
Advice about finding information from the internet is generally very poor with 67% of all patients not receiving any guidance on using the internet to find accredited information. However, patients with a CNS are far more likely to be directed to trusted websites compared to those without a CNS.

Over 60% of patients use the internet for further information and those with CNS access are more likely to say it was useful (54%) compared to those without a CNS (49%). This demonstrates the importance of referring patients to trusted websites.

## Additional hospital support VS CNS provision

Referring back to question 49 (were you offered additional support in any of the following areas?), which we used to identify patients who had access to a CNS, we wanted to identify what support patients were offered as an alternative to a CNS.

### The percentage of patients offered additional support:



Disappointingly, 66% of patients without CNS access were not offered any alternative support. Only 13% of patients without a CNS said they didn't need any support, suggesting there is a huge gap between those who want support and those who receive it.

Patients with a CNS were also more likely to be offered other support including: counselling, buddies or befriending, and support groups.

75% of patients offered a CNS accessed the alternative support, and 9 out of 10 of these patients said it helped them to feel better/more positive.

Of those not offered a CNS, only 59% accessed the alternative support offered to them and only 7 out of 10 said it helped them feel better/more positive.

These results suggest that access to a CNS is one of the best means of additional support for patients. Helping them to feel better or more supported and also ensuring they have greater options for further support should they require it.

## ACCESSING A CNS: REGIONAL ACCESS

### Regional access across the UK

From our anonymous online survey cohort we were able to look at differences in access across UK countries.

Results suggest that CNS access is poorer in Scotland and Wales compared to England. It must be noted, however, that the majority of respondents (94%) were from England and the numbers for elsewhere are very small in comparison. More data would, therefore, be needed to confirm this trend.

	Offered Access to a CNS	Not Offered Access to a CNS	TOTAL
England	742 (39%)	1150 (61%)	1892
Scotland	12 (21%)	45 (79%)	57
Wales	13 (32%)	28 (68%)	41

\*Northern Ireland data excluded due to there being fewer than 15 responses.

### Regional access across England by Strategic Clinical Network (SCN)

There are 12 SCNs and they were implemented to improve integration and communication between care providers at each stage of the patient pathway<sup>ix</sup> (for more information on which Trusts fall into each SCN, see Appendix 1).

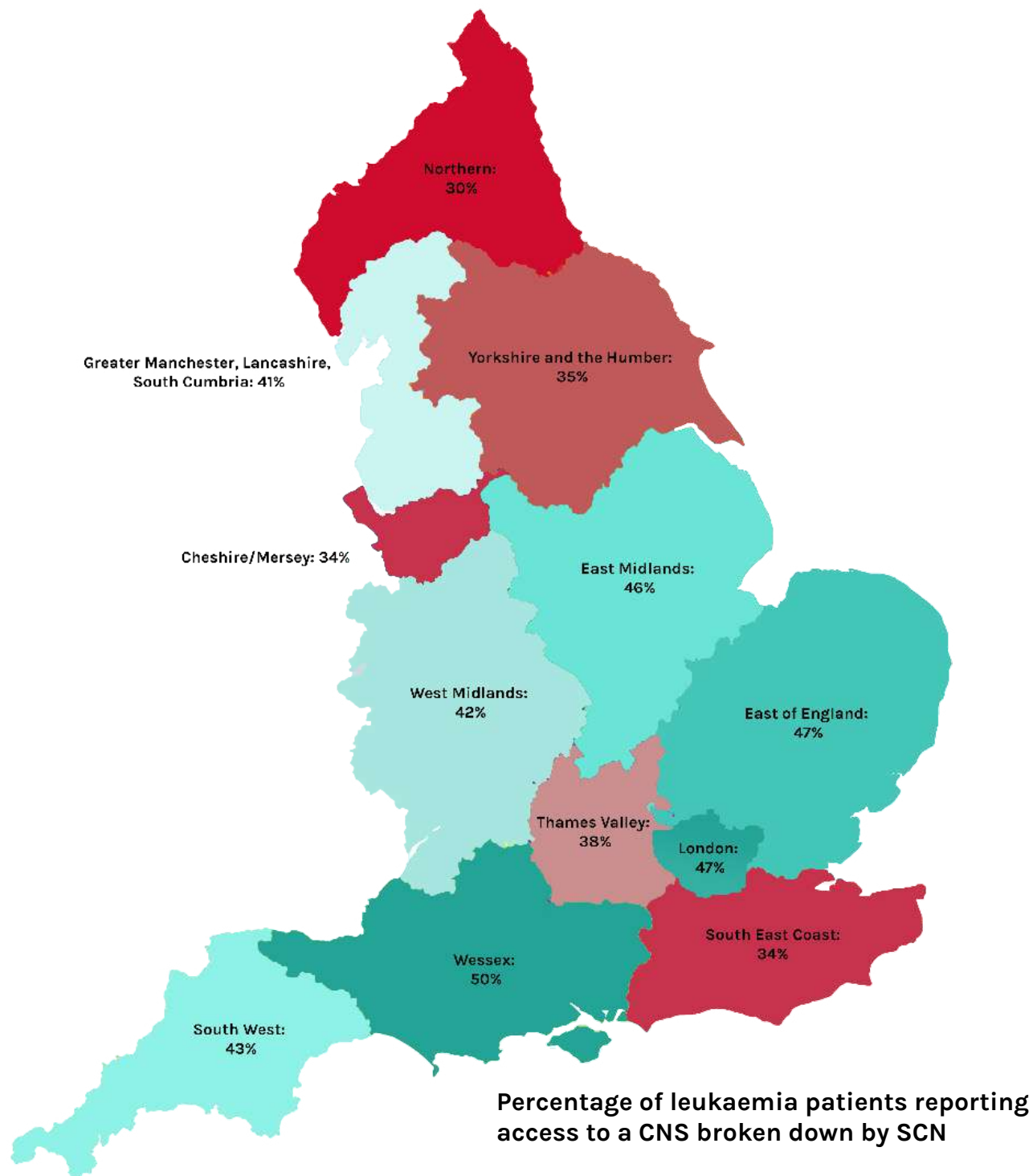
Variations in healthcare across regions are something known, but not readily quantified. Here we use the CPES cohort (arm 1) of the patient experience survey to identify and quantify the regional variations in CNS access across England.

From the CPES cohort, 1320 patients out of 2019, we were able to identify which strategic network each patient was in and therefore, determine the differences in CNS access across the networks. We identified that the average number of patients with CNS access across SCNs was 41%, which is higher than the figure stated on page 12 (38%). This demonstrates that patients within the charity cohort were less likely to have access to a CNS and therefore suggests that those without CNS access reach out to charities for support.

As predicted, there were significant variations in CNS access across the regions. The lowest level of access was just 30% of patients in the Northern SCN and the highest was 50% in the Wessex SCN.

Regional breakdown of CNS access based on Strategic Clinical Network:

1320 patients in the Leukaemia Care survey reported on whether or not they had access to a CNS. This was then split between each Strategic Clinical Network to reveal the regional breakdown which can be seen below:



## CNS ACCESS – FREEDOM OF INFORMATION (FOI) REQUESTS

We sent out Freedom of Information requests to hospital trusts across England to gather information on the change in CNS numbers since the 2015 Cancer Strategy was first published and determine other issues that could be affecting patient's access to a CNS.

We sent out 210 FOI requests on 2 October 2017 and, as of 13 November 2017:

72 trusts had confirmed they do not provide direct care for blood cancer patients. Meaning approximately 138 trusts do treat blood cancers.

78 of the 138 trusts had provided responses to the request, equating to a response rate of 56.5%.

Of the 60 trusts yet to respond, 9 had confirmed there would be a delay in providing the information.

### CNS numbers

For CNS numbers we asked separately for the number of haematology, blood cancer specific and leukaemia specific Clinical Nurse Specialists in the trust in both May 2015 and September 2017.

The numbers below show the total working time equivalent (WTE) Clinical Nurse Specialists across 77 trusts in 2015 and 2017 – one trust had to be excluded from this as they did not provide figures for 2015.

	<b>2015</b>	<b>2017</b>	<b>Percentage increase</b>
<b>Haematology CNS</b>	239.68 WTE	293.9 WTE	18.4%
<b>Blood Cancer Specific CNS</b>	114.11 WTE	151.18 WTE	24.5%
<b>Leukaemia specific CNS</b>	25.28 WTE	31.7 WTE	20.3%

The figures show a promising increase in the numbers of Clinical Nurse Specialists, both general and specialist. The percentage increase in haematology CNS numbers between 2015 and 2017 also appears to be higher than between 2011 and 2014 (15.8%), as deduced from the Macmillan Nursing Consensus<sup>x</sup>. However, the differences in response rate must be considered, 56.5% compared to 96.5% respectively.

The numbers of blood cancer specific and leukaemia specific nurses have increased over the past two years, but the distribution of these Clinical Nurse Specialists across trusts is significantly different.

Out of 78 trusts, 46% of trusts (36) stated that they only had haematology Clinical Nurse Specialists i.e. those generic to all malignant and non-malignant haematological disorders. Working across 21 different trusts, there are only 31.7 WTE leukaemia-specific Clinical Nurse Specialists. This equates to just over 1 in 4 NHS trusts caring for leukaemia patients having a leukaemia specialist CNS.

## CNS numbers across England by Strategic Clinical Network

We were able to identify the percentage increase in working time equivalent (WTE) Clinical Nurse Specialists across the strategic clinical networks from the information provided within FOI requests.

It was found that between May 2015 and September 2017 the WTE of haematology Clinical Nurse Specialists (including those specialised to blood cancers) has increased on average by approximately 19.2% across SCNs\*. This increase varied significantly across regions from a 7.4% increase in WTE CNS in the South East Coast SCN to a 32.2% increase in the Wessex SCN.

\*This number excludes the Cheshire and Mersey SCN as complete numbers for 2015 and 2017 were not obtained.

### Percentage increase of haematology clinical nurse specialists by Strategic Clinical Network:



## **NHS burden**

Nursing vacancies account for the one of the largest NHS staff shortfalls. The guidance for safe staffing levels required 24,000 additional nursing posts to be created between 2012 and 2015. Health Education England identified that this contributed to the 26,700 nursing vacancies across the UK, as of April 2015. Across regions, the vacancies varied from 5.4% in the North East to 13.8% in South London<sup>xi</sup>.

## **NHS burden: demand vs availability**

Without knowing the caseloads of Clinical Nurse Specialists at different trusts, it is difficult to assess whether the regional variations in CNS access are attributable to CNS numbers and their patient caseload.

We attempted to gather this information through the FOI requests, but unfortunately the information that trusts could provide significantly differed. This meant that from the data gathered we could not gather a true representation of CNS caseloads across the UK.

However, another question asked within the FOI requests was whether the Clinical Nurse Specialists were required to undertake normal ward duties. In almost 3 in 4 trusts the Clinical Nurse Specialists were not required to undertake normal nursing duties.

At the majority of other trusts, the Clinical Nurse Specialists were not ordinarily required to undertake ward duties except in times of increased pressure on the nursing staff levels. Some specifically stated this as over the winter period, when the burden on the NHS has in recent years been a lot higher.

## **NHS burden: CNS training**

18 out of 78 trusts (23%) stated they had future plans for increasing the CNS workforce. In some cases they stated that CNS numbers would be increased in line with increased demand, which is a good position to have to ensure that CNS access is maintained with the rise in leukaemia cases.

Some are developing business cases to prove the value of increasing the CNS workforce, as one trust stated that they have highlighted the need for an additional CNS for several years without any change.

Other trusts are in the process of training a band-6 nurse practitioner or recruiting, and one stated specifically that they had funding for 2 Macmillan nurses.

## RECOMMENDATIONS

The findings of this report clearly echo those of previous studies, demonstrating how key Clinical Nurse Specialists are for improving the experience of leukaemia patients in the UK. This ultimately reiterates the importance of fulfilling the Cancer Strategy aim of ensuring all cancer patients have access to a CNS.

We have made the following three recommendations for improving CNS access across the UK:

### 1) Ensuring that patients are introduced to their CNS from diagnosis.

*"It would appear it has been rare to have a nurse in the first appointment, and still is, even though it has been best practice for some time." [Andy, CLL patient]*

Having a CNS in the first diagnosis appointment can make a huge impact for the subsequent journey of a patient. Ensuring that patients have met their CNS and spoken with them at an early stage could make the difference between patients simply being given the name of their CNS, and patients feeling as though they have access to a CNS.

### 2) Increasing the specialisation of Clinical Nurse Specialists.

In many trusts, the haematology Clinical Nurse Specialists are either general to both malignant and non-malignant disorders, or general to all blood cancers. While there will be overlapping issues faced by these patients, there are significant differences between disease types. This puts significant pressures on a CNS who is required to have in-depth knowledge of each disorder; including physical and psycho-sociological impacts and ways to best manage the patients.

Dividing the work force in a disease-type specific manner could, therefore, help to alleviate this pressure on the CNS, improve staff training in specific disease areas and ensure that patients are receiving the best possible management of their blood cancer type.

### 3) A general improvement in nursing staff levels across the NHS.

The hardest task of all, but arguably most crucial, is to ensure that CNS levels are keeping pace with the ever increasing number of cancer patients and increasing in line with the Cancer Strategy. Positive steps have been made in achieving this and both financial support and training from charities, such as Macmillan, have played a role in the increasing numbers.

The current shortfall in nursing levels may, however, quickly become an issue for nurses training and progressing to CNS level, because they will be required to remain in nursing roles. This is already an issue observed at certain times of the year with Clinical Nurse Specialists being required to undertake normal ward duties during particularly pressured times. While many trusts attempt to avoid this, it is crucial to ensure that nursing staff are supported and patients are not put at undue risk.

If the nursing vacancy issues aren't resolved, this could eventually lead to a plateau of CNS numbers, when there are already clear issues with CNS availability for the demand. Ultimately this has implications for the wellbeing of blood cancer patients and could lead to increased pressure on GPs and A&E.



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## APPENDICES

### APPENDIX 1

**Hospital trusts divided by strategic clinical network (SCN) – this list includes the 137 hospital trusts that provide blood cancer care, as deduced from Freedom of Information (FOI) Requests**

(correct as of 13.11.2017)

#### Cheshire and Mersey (North West Coast)

Trusts	FOI request data received?
Aintree University Hospital NHS Foundation Trust	Yes
Countess of Chester Hospital NHS Foundation Trust	Yes
East Cheshire NHS Trust	Yes
Mid Cheshire Hospitals NHS Foundation Trust	Yes
St Helens and Knowsley Hospitals NHS Trust	Yes
The Clatterbridge Cancer Centre NHS Foundation Trust	Yes
Warrington and HaltonHospitals NHS Foundation Trust	No
Wirral University Teaching Hospital NHS Foundation Trust	No

#### East Midlands

Trusts	FOI request data received?
Chesterfield Royal Hospital NHS Foundation Trust	No
Derby Teaching Hospitals NHS Foundation Trust	Yes
Kettering General Hospital NHS Foundation Trust	Yes
Northampton General Hospital NHS Trust	Yes
Northern Lincolnshire and Goole NHS Foundation Trust	Yes
Nottingham University Hospitals NHS Trust	Yes
Sherwood Forest Hospitals NHS Foundation Trust	No
United Lincolnshire Hospitals NHS Trust	No
University Hospitals Of Leicester NHS Trust	Yes

#### East of England

Trusts	FOI request data received?
Basildon and Thurrock University Hospitals NHS Foundation Trust	No
Bedford Hospital NHS Trust	No
Cambridge University Hospitals NHS Foundation Trust	Yes
Colchester Hospital University NHS Foundation Trust	Yes

East and North Hertfordshire NHS Trust	No
Ipswich Hospital NHS Trust	Yes
James Paget University Hospitals NHS Foundation Trust	No
Luton and Dunstable University Hospital NHS Foundation Trust	Yes
Mid Essex Hospital Services NHS Trust	No
Norfolk and Norwich University Hospitals NHS Foundation Trust	Yes
Norfolk Community Health and Care NHS Trust	No
North West Anglia NHS Foundation Trust	Yes
Southend University Hospital NHS Foundation Trust	No
The Princess Alexandra Hospital NHS Trust	Yes
The Queen Elizabeth Hospital, King's Lynn. NHS Foundation Trust	No
West Hertfordshire Hospitals NHS Trust	Yes
West Suffolk NHS Foundation Trust	Yes

## Greater Manchester, Lancashire and S. Cumbria

Trusts	FOI request data received?
Blackpool Teaching Hospitals NHS Foundation Trust	No
Bolton NHS Foundation Trust	No
East Lancashire Hospitals NHS Trust	Yes
Lancashire Teaching Hospitals NHS Foundation Trust	Yes
Manchester University NHS Foundation Trust	Yes
Pennine Acute Hospitals NHS Trust	Yes
Salford Royal NHS Foundation Trust	Yes
Southport and Ormskirk Hospital NHS Trust	No
Stockport NHS Foundation Trust	No
Tameside Hospital NHS Foundation Trust	No
The Christie NHS Foundation Trust	No
University Hospitals Of Morecambe Bay NHS Foundation Trust	Yes
Wrightington, Wigan and Leigh NHS Foundation Trust	Yes

## London

Trusts	FOI request data received?
Barts Health NHS Trust	Yes

Chelsea and Westminster Hospital NHS Foundation Trust	Yes
Croydon Health Services NHS Trust	No
Dartford and Gravesham NHS Trust	Yes
Epsom and St Helier University Hospitals NHS Trust	Yes
Guy's and St Thomas' NHS Foundation Trust	No
Imperial College Healthcare NHS Trust	No
King's College Hospital NHS Foundation Trust	No
Lewisham and Greenwich NHS Trust FOI	Yes
London North West Healthcare NHS Trust	No
North Middlesex University Hospital NHS Trust	No
Royal Free London NHS Foundation Trust	Yes
The Hillingdon Hospitals NHS Foundation Trust	Yes
The Royal Marsden NHS Foundation Trust	Yes
The Whittington Hospital NHS Trust	Yes
University College London Hospitals NHS Foundation Trust	Yes
Barking, Havering and Redbridge University Hospitals NHS Trust	No
St George's University Hospitals NHS Foundation Trust	No

## Northern

Trusts	FOI request date received?
City Hospitals Sunderland NHS Foundation Trust	No
County Durham and Darlington NHS Foundation Trust	Yes
Gateshead Health NHS Foundation Trust	Yes
North Cumbria University Hospitals NHS Trust	Yes
Northumbria Healthcare NHS Foundation Trust	No
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	No

## South East Coast

Trusts	FOI request data received?
Ashford and St Peter's Hospitals NHS Foundation Trust	No
Brighton and Sussex University Hospitals NHS Trust	Yes
East Kent Hospitals University NHS Foundation Trust	Yes
East Sussex Healthcare NHS Trust	Yes
Frimley Health NHS Foundation Trust	Yes

Kingston Hospital NHS Foundation Trust	Yes
Maidstone and Tunbridge Wells NHS Trust	No
Medway NHS Foundation Trust	Yes
Royal Surrey County NHS Foundation Trust	Yes
Surrey and Sussex Healthcare NHS Trust	Yes
Western Sussex Hospitals NHS Foundation Trust	Yes

## South West

Trusts	FOI request data received?
Gloucestershire Hospitals NHS Foundation Trust	No
Great Western Hospitals NHS Foundation Trust	Yes
Northern Devon Healthcare NHS Trust	No
Plymouth Hospitals NHS Trust	No
Royal Cornwall Hospitals NHS Trust	Yes
Royal Devon and Exeter NHS Foundation Trust	Yes
Royal United Hospitals Bath NHS Foundation Trust	Yes
Salisbury NHS Foundation Trust	No
Taunton and Somerset NHS Foundation Trust	No
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust	No
Torbay and South Devon NHS Foundation Trust	Yes
University Hospitals Bristol NHS Foundation Trust	No
Weston Area Health NHS Trust	No
Yeovil District Hospital NHS Foundation Trust	No

## Thames Valley

Trusts	FOI request data received?
Buckinghamshire Healthcare NHS Trust	Yes
Milton Keynes University Hospital NHS Foundation Trust	No
Oxford University Hospitals NHS Foundation Trust	Yes
Royal Berkshire NHS Foundation Trust	Yes

## Wessex

Trusts	FOI request data received?
Dorset County Hospital NHS Foundation Trust	Yes

Hampshire Hospitals NHS Foundation Trust	No
Isle Of Wight NHS Trust	Yes
Poole Hospital NHS Foundation Trust	Yes
Portsmouth Hospitals NHS Trust	No
University Hospital Southampton NHS Foundation Trust	Yes

## West Midlands

Trusts	FOI request data received?
Birmingham Women's NHS Foundation Trust	No
Burton Hospitals NHS Foundation Trust	Yes
George Eliot Hospital NHS Trust	Yes
Heart Of England NHS Foundation Trust	Yes
Sandwell and West Birmingham Hospitals NHS Trust	No
Shrewsbury and Telford Hospital NHS Trust	Yes
South Warwickshire NHS Foundation Trust	No
The Dudley Group NHS Foundation Trust	Yes
The Royal Wolverhampton NHS Trust	No
University Hospital Birmingham NHS Foundation Trust	No
University Hospitals Coventry and Warwickshire NHS Trust	Yes
University Hospitals of North Midlands	Yes
Walsall Healthcare NHS Trust	No
Worcestershire Acute Hospitals NHS Trust	Yes
Worcestershire Health and Care NHS Trust	No
Wye Valley NHS Trust	No

## Yorkshire and the Humber

Trusts	FOI request data received?
Airedale NHS Foundation Trust	Yes
Barnsley Hospital NHS Foundation Trust	No
Bradford Teaching Hospitals NHS Foundation Trust	No
Calderdale and Huddersfield NHS Foundation Trust	Yes
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Yes
Harrogate and District NHS Foundation Trust	No
Hull and East Yorkshire Hospitals NHS Trust	No
Leeds Teaching Hospitals NHS Trust	Yes
Mid Yorkshire Hospitals NHS Trust	Yes

North Tees and Hartlepool NHS Foundation Trust	Yes
Sheffield Teaching Hospitals NHS Foundation Trust	Yes
South Tees Hospitals NHS Foundation Trust	No
The Rotherham NHS Foundation Trust	No
York Teaching Hospital NHS Foundation Trust	Yes

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