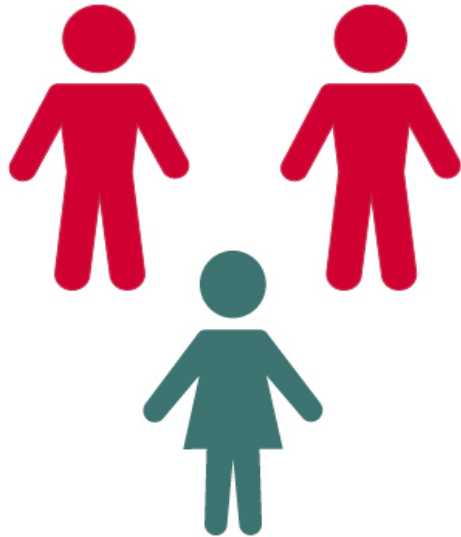


Leukaemia: I wasn't born yesterday



64% of leukaemia cases are diagnosed in people aged 65 and over



81% of leukaemia deaths occur in people aged 65 or older

Age and Inequalities: Exploring the variations in patient experience in different age groups



Older patients are **twice as likely** to die from leukaemia than younger patients



740 deaths of people over the age of 65 could be prevented each year if UK survival rates for leukaemia matched the best in Europe



We undertook a survey of **1305 leukaemia patients** to uncover the inequalities that may be impacting on cancer survival and the experiences of leukaemia patients at different ages

Leukaemia Care
YOUR Blood Cancer Charity

Contents

| | |
|-------------------------------|----|
| Executive Summary | 4 |
| Leukaemia and Age | 5 |
| Mortality | 7 |
| Leukaemia CARE Patient Survey | 9 |
| Information and Understanding | 10 |
| Support | 11 |
| Reduced Urgency | 12 |
| Treatment | 14 |
| Stem Cell Transplants | 15 |
| Clinical Trials | 16 |
| Living with Leukaemia | 17 |
| Recommendations | 18 |
| References | 19 |

What is the problem?

Research from sources such as EUROCARE, Cancer Research UK and Macmillan Cancer Support has extensively shown that cancer survival worsens with increasing age.

What did we do?

We investigated these sources for leukaemia specific information. We found that older patients (those aged 65 and over) make up just under two thirds of all newly diagnosed cases of leukaemia – 64.2%. However, this group accounts for 81% of all leukaemia related deaths. This means that older patients are more than twice (2.4 times) as likely to die from their leukaemia.

We also undertook a survey of 1305 leukaemia patients, to uncover the inequalities that may be impacting on cancer survival and the experiences of leukaemia patients at different ages.

What did we find?

Ten key findings from our survey:

Diagnosis



GPs were **twice as likely** to refer older patients as a non-urgent referral (i.e. cancer was not suspected)



Older patients were **less likely** to know that leukaemia is a type of cancer, only **77%** knew this before they were diagnosed



20% of patients over 65 had not been told about their prognosis when they were diagnosed



Only **two thirds (67%)** of older patients received information about the different types of support available



Older patients were **less likely** to be given guidance on using the internet. **0%** of over 85's given guidance about using online information

Living with Leukaemia



29% of leukaemia patients over the age of 65 were still working



Only **37%** of older patients have access to a Clinical Nurse Specialist (CNS)



Older patients were **nearly twice as likely** to undergo watch and wait, but less likely to understand the reasons for this



Older patients were **less likely** to be given the option of joining a clinical trial (46% v 60%)



Older patients were also **less likely** to have received a stem cell transplant (12% v 37%)

Leukaemia is a cancer which starts in blood-forming tissue, usually the bone marrow. It leads to the over-production of abnormal white blood cells, the part of the immune system which defends the body against infection.

Over 9,500 people are diagnosed with leukaemia in the UK every year¹.

Are there different types of leukaemia?

There are a number of different types of leukaemia, but the four most common are:

1. Acute myeloid leukaemia (AML) - Rapidly developing, affects myeloid cells (granulocytes)²
2. Chronic myeloid leukaemia (CML) - Slowly developing, affects myeloid cells (granulocytes)³
3. Acute lymphoblastic leukaemia (ALL) - Rapidly developing, affects lymphocytes⁴
4. Chronic lymphocytic leukaemia (CLL) - Slowly developing, affects lymphocytes⁵

Acute leukaemia progresses rapidly unless effectively treated, but it can sometimes be cured with standard treatments, such as bone marrow transplants. Chronic leukaemia progresses slowly and although it is not usually possible to cure chronic leukaemia with standard treatments, it can be treated and managed as a long-term condition.

Isn't that just for children?

Like most cancers, leukaemia is a condition that varies greatly by age. However, contrary to popular perception, leukaemia is not just a childhood disease.

It is true that leukaemia is the most common cancer in children, accounting for over 30% of childhood cancers⁶. However, fewer than 7%⁷ of leukaemia cases are diagnosed in children and teenagers.

“I had heard of Leukaemia but I thought it was a childhood illness.”
CLL patient, (65 - 69)

Who does it affect then?

In fact, leukaemia incidence correlates strongly with increasing age, with nearly 65% (64.2%) of cases diagnosed in people aged 65 and over⁸.



64% of leukaemia cases are diagnosed in people aged 65 and over

This is the same for most cancer types, with 65.8% of all cancer cases in the UK diagnosed in those aged 65 and over⁹.

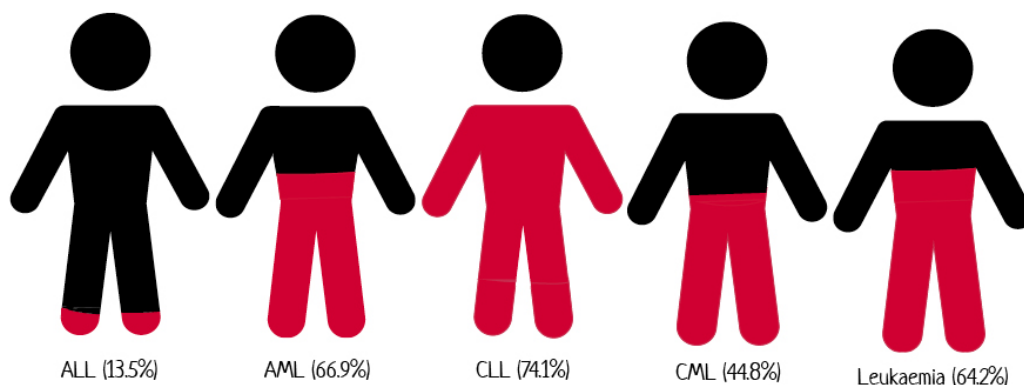
An exception to this rule is acute lymphoblastic leukaemia (ALL), where the majority of cases (55%)¹⁰ are diagnosed in children, aged 14 and under.

As the UK population is getting older, the number of older people living with cancer is also increasing, doing so at a faster rate than any other age group²¹.



| Age Group | Leukaemia Incidence | |
|-----------|---------------------|----------------|
| | Number | Percentage (%) |
| 0 to 64 | 3403 | 35.8 |
| 65+ | 6110 | 64.2 |
| Total | 9514 | 100 |

| Leukaemia Type | Number of cases diagnosed in over 65s each year | Percentage of cases diagnosed in over 65s (%) |
|-------------------------------------|---|---|
| Acute lymphoblastic leukaemia (ALL) | 104 (of 772) ¹¹ | 13.5 ¹² |
| Acute myeloid leukaemia (AML) | 2011 (of 3006) ¹³ | 66.9 ¹⁴ |
| Chronic lymphocytic leukaemia (CLL) | 2652 (of 3576) ¹⁵ | 74.1 ¹⁶ |
| Chronic myeloid leukaemia (CML) | 354 (of 731) ¹⁷ | 48.4 ¹⁸ |
| Leukaemia (all subtypes) | 6110 (of 9514)¹⁹ | 64.2²⁰ |



Leukaemia mortality is also strongly related to age, with the highest mortality rates in older patients.

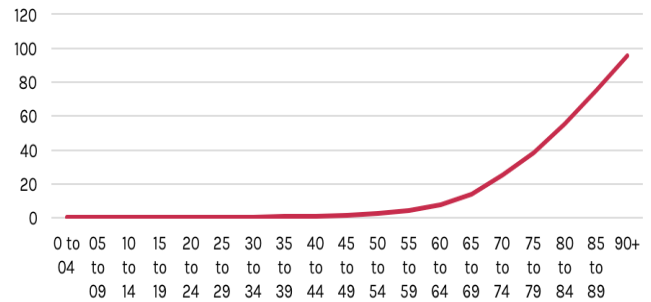
Somebody aged 65 or older in the general population is 21 times²² more likely to die from leukaemia than somebody aged 64 or younger (35.4 deaths per 100,000 v 1.69 deaths per 100,000). On average, 81%²³ of leukaemia related deaths occur in people aged 65 and over.



4 in 5

81% of leukaemia deaths occur in people aged 65 or older

Number of deaths per 100,000 people

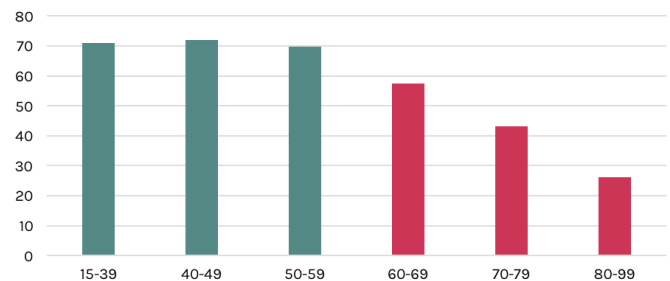


Somebody aged 65 and over diagnosed with leukaemia is more than twice²³ (2.4 times) as likely to die from their leukaemia than a younger patient (62.6% v 26.0%). Breaking this down by leukaemia type - ALL 4.2 times (85% v 20%), AML 1.9 times (99% v 53%), CLL 3.7 times (39% v 10%), CML 5.5 times (53% v 9%). However, at the time of diagnosis, patients over 65 were less likely to be told about their prognosis (20% not told v 14%).

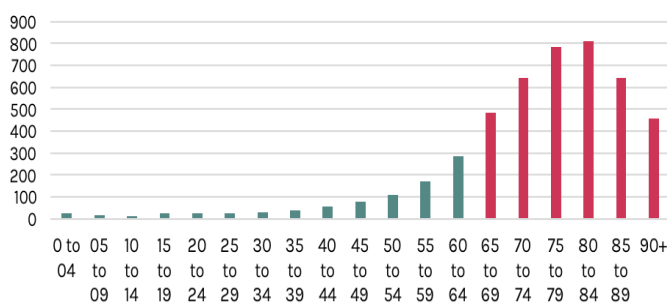
Five Year Survival

Cancer Research UK data shows that the percentage of patients surviving for five years or more following a leukaemia diagnosis decreased as age increased²⁵. This data has been adjusted to take into account higher mortality from other causes in older people.

Expected Five Year Survival (%) - Leukaemia



Number of deaths



Age-specific mortality rates (number of deaths per 100,000 of a particular age group) rise sharply from around 65, with the highest rates in the oldest age groups.

European Comparison

The UK has some of the worst cancer survival outcomes in Europe, with survival differences for both haematological and solid tumours²⁶.

The EUROCARE 5²⁷ study highlighted persistent five-year survival differences between European regions, based on variations in quality of care and the availability of new treatments²⁸. For most types of blood cancer, the UK had significantly poorer survival outcomes than Northern, Central and Southern Europe (but higher than Eastern Europe)²⁹. For example, the approval of new drugs occurred earlier and uptake was greater in France than UK. The survival outcomes were higher for all haematological malignancies in France than the UK³⁰.

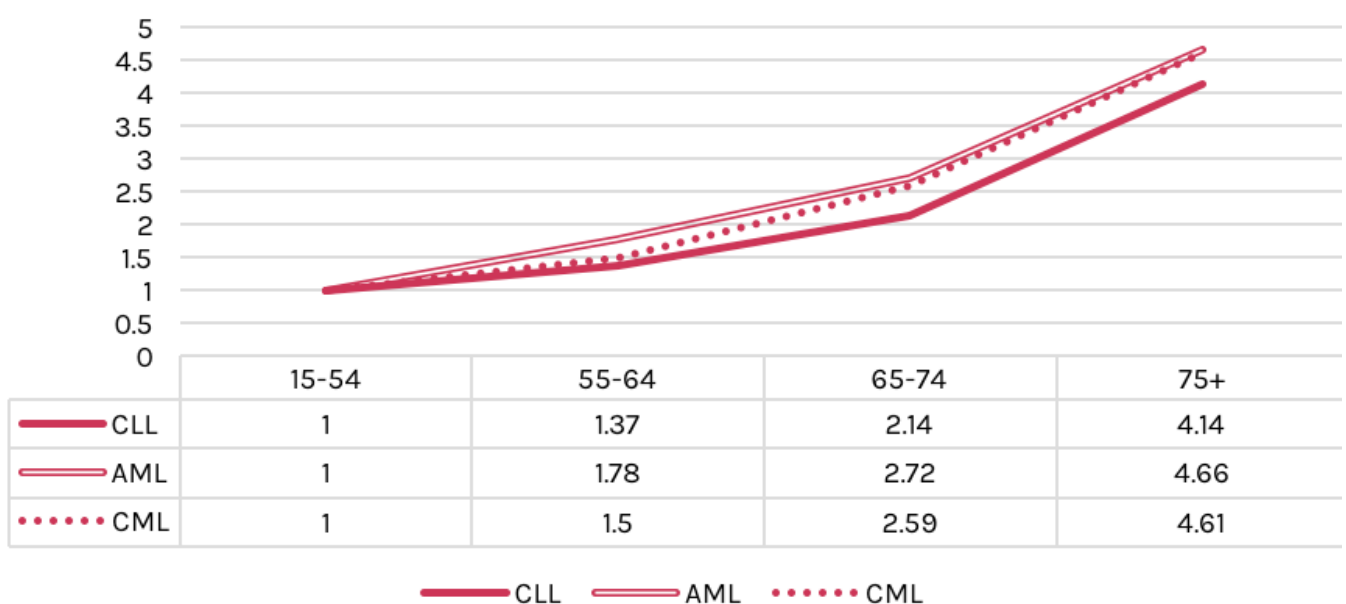
EUROCARE also found that throughout Europe, blood cancer survival decreased with advancing age³¹. The excess risk of death increased significantly with age for all types of blood cancer, particularly for patients aged 75 and older. For each haematological malignancy, younger patients had a better five-year survival than older patients and the survival improvement over time was generally greater in younger than older patients³².

The figure below uses age 15-54 as a reference (where the relative risk of death = 1), to show how the excess risk of death increases for each leukaemia type as age increases.

Macmillan Cancer Support's 'Age Old Excuse'³³ report found that "there are thousands of older patients dying unnecessarily from cancer every year"³⁴. They highlighted a number of factors, including under treatment, that are leading to "unacceptably poor cancer survival rates among Britain's older population"³⁵.

There are currently over 4,700 lives lost to leukaemia each year in the UK³⁶. An analysis of the EUROCARE mortality data shows that if UK survival matched the best in Europe³⁷, over 900 lives could be saved each year, including 740 people aged 65 and over³⁸. If we do not address the survival issues with over 65s, we cannot address cancer survival issues generally (because most patients are older).

EUROCARE - Excess Risk of Death - By Age



Leukaemia CARE Patient Survey



Throughout 2016, Leukaemia CARE undertook a survey of 1320 leukaemia patients.

These were adult leukaemia patients (16+) who had previously responded to NHS England's Cancer Patient Experience Survey (CPES)³⁹ and had agreed to be contacted again for further research. CPES is carried out annually by external survey provider, Quality Health.

The survey questionnaire was developed by Leukaemia CARE and Quality Health, including reviews from a group of patient testers. The survey questionnaire was designed to follow a patient through their journey, covering diagnosis, treatment, care and support.

| | Age Band | Number | Percentage |
|--------------------------|------------|-------------|-------------|
| Under 65 (499) | 16 - 24 | 21 | 1.6% |
| | 25 - 34 | 23 | 1.7% |
| | 45 - 54 | 124 | 9.4% |
| | 55 - 64 | 284 | 21.5% |
| 65 and Over (806) | 65 - 74 | 469 | 35.5% |
| | 75 - 84 | 277 | 21.0% |
| | 85+ | 60 | 4.6% |
| Unknown | N/A | 15 | 1.1% |
| Total | All | 1320 | 100% |

The final version of the survey was mailed out to 1711 patients (of whom 28 were subsequently excluded, as having moving or deceased), with a response rate of 78%.

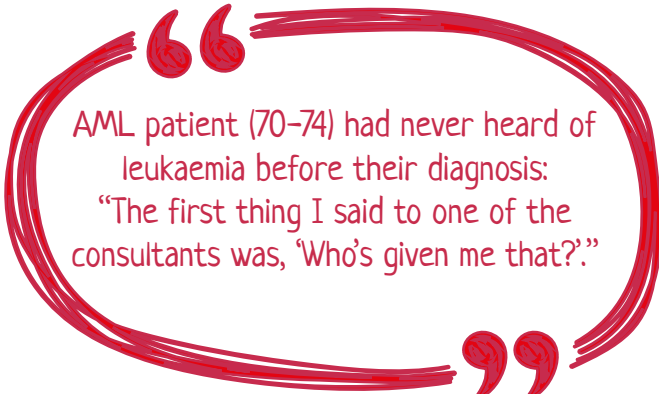
The purpose of this survey was to highlight inequalities in the experiences of leukaemia patients. This report compares and contrasts the experiences of those aged under 65 (16-64) against those aged 65 and older, to highlight differences in their experiences. Of the 1320 patient responses, 15 chose not to answer the age banding question, so they have been excluded from this age breakdown analysis.

The responses were sorted (using CPES data) into categories based on their confirmed diagnosis:

| Confirmed Diagnosis | Number | Percentage | |
|--|--|-------------|------|
| Acute lymphoblastic leukaemia (ALL) | 87 | 6.7% | |
| Acute myeloid leukaemia (AML) | 286 | 21.9% | |
| Chronic lymphocytic leukaemia (CLL) | 664 | 50.9% | |
| Chronic myeloid leukaemia (CML) | 109 | 8.4% | |
| Other leukaemia | Hairy cell leukaemia (HCL) | 47 | 3.6% |
| | Acute promyelocytic leukaemia (APML) | 52 | 4.0% |
| | Chronic myelomonocytic leukaemia (CMML) | 25 | 1.9% |
| | All other leukaemia types | 35 | 2.7% |
| Total | 1305 | 100% | |

This report also draws together wider findings from other external sources, to present leukaemia specific findings, to inform this analysis. Wherever relevant, these have been referenced to the appropriate sources.

Whilst overall awareness of leukaemia was high, patients over the age of 65 were less likely to know leukaemia was a type of cancer before they were diagnosed (77% v 81% of patients under 65).



AML patient (70-74) had never heard of leukaemia before their diagnosis:
“The first thing I said to one of the consultants was, ‘Who’s given me that?’”

Information

Patients aged 65 and over were less likely to receive information about support for their condition (only 67% v 78% under 65).

However, this is likely to have been influenced by the fact that a larger number of patients in this group reported that they did not want or need information (21% v 9%). Of those who received information, patients aged 65 and over were more likely to receive just verbal information (15% v 9%). More worryingly, across both groups, 11% of patients wanted information but did not receive it.

Patients aged 65 and over also rated the information more highly. Whilst there were no differences in the number of people reporting difficulties understanding most of it (3% for each), patients aged 65 and over were more likely to report understanding ‘all of it’ (70% v 66%). The remainder (27% v 31%) said they understood some of it.

Additional Information

Patients aged 65 and over were also less likely to be recommended further information (27% not recommended anything v 22%). They were less likely to be made aware of the support available from charities (7% v 9% told about Leukaemia CARE and 12% v 19% told about other organisations).

These differences were particularly dramatic with regards to online information. Patients aged 65 and over were less likely to be given guidance on using the internet (56% v 81%). This difference was particularly stark for the 85+ age group, with 100% of patients (45/45) saying they were not told about using online information.

Recent data from the Office of National Statistics⁴⁰ shows that internet usage is on the rise. Of those aged 65-75, 74% had recently used the internet. Additionally, 39% of over 75s had recently used the internet, which had nearly doubled between 2011-2016 to 2016-2021.

Whilst it is true that patients in the 65+ group were less likely to use the internet to find information (43% v 64%), this still represents a large proportion of patients. Furthermore, those who did use the internet in the 65 and over group were more likely to find it useful than younger patients (85% v 78%). As such, there is a clear need for guidance about the use of the internet, so that patients can tailor their usage to validated websites.

We also asked patients about additional support, such as counselling, support groups or access to a clinical nurse specialist (CNS).

Older patients reported that they were less likely to get support, from either the hospital's own services or charities (20% didn't v 15%).

Overall, patients aged 65 and over were less likely to be offered additional support (44% not offered v 29%). However, of those who were offered additional support, they were just as likely to access it (68/69%) and just as likely to find it beneficial (87%).

Clinical Nurse Specialists

Most worryingly, older patients were less likely to be offered access to a CNS (37% v 49%), which is the factor most likely to be associated with high patient satisfaction⁴¹. This is significantly different for both age groups from the Cancer Patient Experience Survey figure of 79%⁴², which reports the number of patients who were given the name of a CNS who would support them. Our question was designed to match the recommendation in the Independent Cancer Taskforce's strategy, which noted the significance of the CNS role and recommended that "all patients should have access to a CNS or other key worker from diagnosis onwards"⁴³. This highlights significant differences between knowing the name of your CNS and being able to access support, possibly due to restrictions in the availability of CNS time.

If people are supported by a CNS "they feel more positive about the care and the treatment they receive"⁴⁴. For each type of leukaemia, access varied - AML (36% 65+ v 54% U65), ALL (64% 65+ v 57% U65), CLL (36% 65+ v 48% U65), CML (36% 65+ v 38% U65) and other leukaemia (32% 65+ v 44% U65). These variations highlight a wider issue with chronic leukaemia patients accessing a CNS, which will have influenced the overall figure, due to the higher number of CLL patients aged 65 and over. However, looking at each leukaemia individually, other than ALL (where the numbers were small), older patients were less likely to be

offered access to a CNS than a younger patient with the same condition.

"I do feel that seeing the same consultant/nurses and having access to more is great, instead of a different one each time you go, or have to contact more"

CLL patient, (85-89)

"I am currently on a funded clinical trial. The one thing I felt the lack of prior to going on the trial, was the provision of a specialist nurse or care professional who I might feel I could contact if I had problems or questions between appointments at a consultant's clinic."

CLL patient, (65-69)

"They have always been there for me and my relative when we had any concerns."

CLL patient, (80-84)

Diagnosis

When presenting with leukaemia patients over the age of 65 were less likely to be treated as an urgent case. Of those presenting to a GP, patients over the age of 65 were more than twice as likely to be treated as a non-urgent referral (i.e. cancer was not suspected), increasing from 19.7% to 40.5% of cases.

Non-urgent referrals were higher in the older age group for all types of leukaemia, but particularly noticeable for AML (14.0% v 7.5%), CML (24.4% v 9.8%) and 'other' leukaemia (45.3% v 14.3%). The differences were less significant for ALL (7.7% v 5.4%) and CLL (49% v 39.1%).

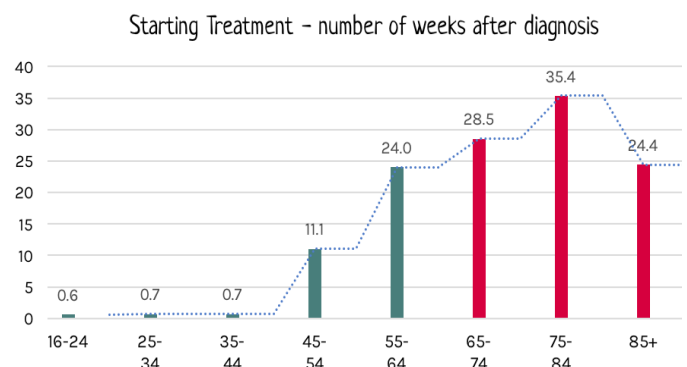
Older people may have other complex health needs, which can make it harder to distinguish potential cancer signs and symptoms from other health issues, and to investigate and refer appropriately⁴⁵. Our survey showed an increased number of patients reporting no symptoms at diagnosis (25% v 9%, with 33% of patients over 85 reporting no symptoms). This was the case for each leukaemia type - ALL (14% v 9%), AML (18% v 3%), CLL (30% v 13%), other leukaemia (16% v 9%), with the exception of CML (7% 65+ v 14% under 65). As a result, patients aged over 65 were also less likely to suspect cancer before they were diagnosed (15% v 20% of under 65s, only 7% in the 85+ group).

“They took too long to start treatment”
CLL patient, (70-74)

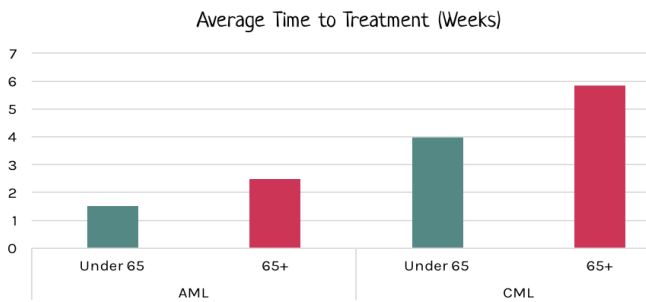
Treatment

Patients aged 65 and over were less likely to start treatment straight after their diagnosis, with only 13% of over 65's starting treatment on the same day (compared to 30% under 65).

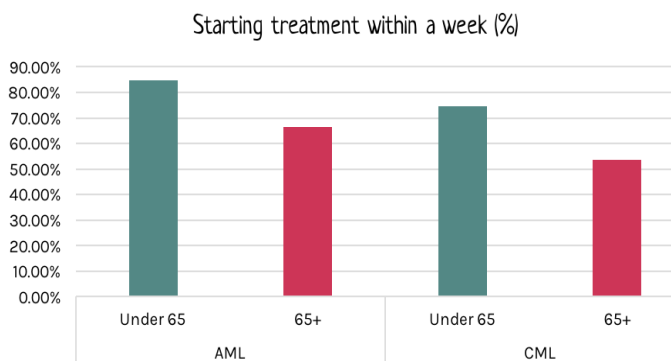
This also translated into a long-term difference, with patients aged 65 and over starting treatment 7 months (30.6 weeks) after diagnosis compared to 3.8 months (16.4 weeks) for under 65s. This difference is heavily influenced by the increased proportion of chronic lymphocytic leukaemia (CLL) patients aged 65 and over. Because of the high rates of watch and wait, CLL patients took an average of 10.7 months (46.5 weeks) from diagnosis to treatment.



The following differences were observed - ALL (5.4 weeks v 1.2); AML (2.5 weeks v 1.5), CML (5.8 weeks v 4.0). For ALL this difference was primarily influenced by a single individual in each group waiting significant amounts of time before starting treatment (in excess of 6 months). If you remove both individuals from the calculation, the time to treatment drops to 0.65 weeks in under 65s and 0.67 weeks in over 65s. However, differences in the time to treatment remain for both AML and CML.



The increased time to treatment for both AML and CML was also reflected in a lower percentage of older patients starting treatment within a week of diagnosis. There were no significant differences the percentage of ALL patients starting treatment within a week of diagnosis.



For all other leukaemia types, older patients were more likely to undergo watch and wait than younger patients - ALL (9.5% v 1.6%), AML (11.1% v 0.7%), CML (7.8% v 3.6%) and other leukaemia (22.4% v 7.6%). It is interesting to note that nobody under the age of 45 was placed on watch and wait (out of 88 patients).

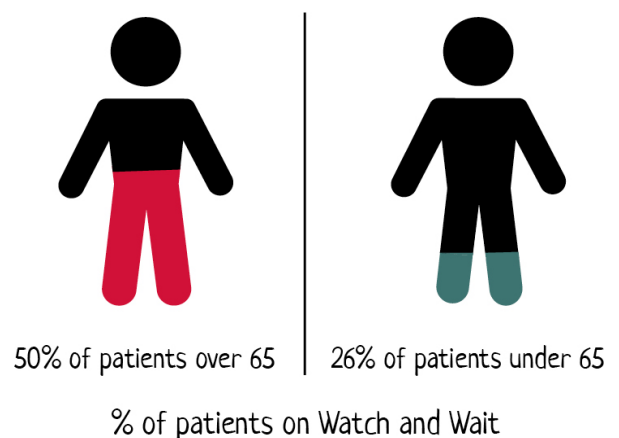
Additionally, older patients were less likely to fully understand the reasons for watch and wait (63% v 69%) and were less likely to receive written information to help address this lack of understanding (32% not given v 28%).

“During treatment my experience of being delayed was not explained properly. I was not aware that I could go a fairly long time between treatments before it mattered.”
 CLL patient, (70-74)

Watch and Wait

Watch and wait refers to a period of monitoring, rather than active treatment. Watch and wait seeks to ensure that patients are not exposed to treatment earlier than necessary, as doing so can build up a resistance, which could limit a patient's future treatment options. Patients are monitored for changes and developments, such as increasing symptoms or disease progression.

Our survey highlighted that older patients were more likely to undergo watch and wait (50% v 26%), because of the higher proportion of CLL patients over the age of 65. However, older CLL patients were less likely to undergo watch and wait than younger CLL patients (69.9% v 76.5%).



Side Effects

Over 65s were also less likely to report side effects, with all side effects lower in the older age group, except bruising (24% v 15%), bleeding (7% v 6%) and other (17% v 15%). Older patients were also more likely to report experiencing no side effects (12% v 8%).

“Side effects, such as bleeding are a problem” (CLL Patient, 80-84)

Looking at the breakdown by leukaemia type, older patients were less likely to report experiencing particular side effects than younger patients with the same condition. Potential reasons for this variation include older patients receiving less-intensive treatment or a reduced willingness to report side effects.

Additionally, older patients were less likely to be hospitalised as a result of side effects (30% v 39%). They also reported a lower impact of side effects, with 71% of patients reporting side effects as 'barely noticeable' or having had a 'small impact' (compared to 58%). However, older patients were also less willing to tolerate additional side effects for a more effective treatment (34% wouldn't v 21% of under 65s).

Preferences

We also investigated treatment preferences, which showed a strong preference for treatment as an outpatient (visiting hospital), with 74% selecting that option (compared to 59% for younger patients). This preference persisted across all leukaemia types.

There was also a reduced interest in receiving oral treatment (45% of patients selected v 60%), this carried across all leukaemia types,

with older patients less likely to select it than younger patients with the same condition. This was particularly evident in the 85+ age group, where intravenous infusion (through a drip) was as popular as oral treatment (37% of patients for both).

Relapse

Overall, patients aged 65 and over were also slightly more likely to have relapsed (29% v 25%). However, this varied between different leukaemia types - ALL (20% v 17%), AML (30% v 30%), CLL (29% v 33%), CML (17% v 15%) and other leukaemia (35% v 16%).

Older patients who had relapsed were more likely to have relapsed multiple times, with 45% patients relapsing two or more times (compared to 24%). For each leukaemia type, older relapsed patients were more likely to have relapsed multiple times than their younger counterparts.

“As an outpatient, the treatment received as been excellent. Brilliant specialist, brilliant nursing staff in all departments. As an inpatient the treatment was absolutely appalling, disrespectful nursing staff, no respect or consideration for the dignity of elderly patients. Shove them in a corner and forget they exist, this happened on several occasions. It needs to be seriously looked at. Outpatients, fantastic for me.”
CLL patient, (65-69)

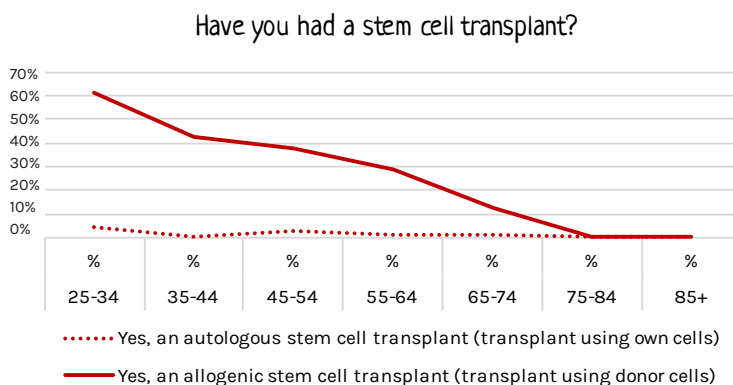
Stem Cell Transplant

Macmillan's 'Age old excuse'⁴⁶ report identified under treatment as a factor contributing to poor survival rates in the older population. They reported that "older people are less likely to receive cancer treatments such as surgery, radiotherapy and chemotherapy than younger people. Often, this is medically justifiable – over treatment is just as undesirable as under treatment – but we can't ignore the growing evidence which suggests that many older patients who could benefit from treatment are not being offered it."⁴⁷ Public Health England have reported that physical suitability for treatment or patient preference alone is unlikely to fully explain the disparity in treatments⁴⁸.

the needs of active older people in otherwise good health are very different from those living with frailty and other conditions⁵⁰.

Whilst stem cell transplants are associated with significant risks, there is evidence that stem cell transplantation is an option for patients over 70⁵¹.

As such, Macmillan's recommendations remain applicable in this situation. Age alone should never be a barrier to treatment⁵². Treatment decisions should be individual, based on their "ability to tolerate treatment, quality of life or personal preferences" rather than chronological age⁵³.



Our survey highlighted that older patients were significantly less likely to receive a stem cell transplant (12% v 37%), the only curative treatment for most types of leukaemia. This difference was observed across all different types of leukaemia - ALL (18% 65+ v 60% U65), AML (35% v 72%), CLL (5% v 9%), CML (7% v 20%) and other leukaemia (15% v 20%). Of the 320 patients aged 75 and above, only two had received a stem cell transplant.

Macmillan highlighted that "people of the same age may have very different needs and will cope with cancer treatments differently"⁴⁹.

Older patients are more likely to experience other issues such as comorbidities, social isolation and difficulties getting to and from hospital. However,

“Advised years ago, as being too old for stem cell therapy.”
CLL patient, (80-84)

“I was disappointed to be told initially that my age put me beyond the cut off point for my procedure. No consideration is given to an individual patient's fitness! I eventually had the procedure months later. So far the consultants says it's been “text book”.”
AML patient, (70-74)

Clinical Trials

Macmillan's 'Age old excuse' report also highlighted a lack of evidence on the effectiveness and safety of cancer treatments in older people as part of the problem⁵⁴.

The EUROCARE report noted that "most clinical trials do not include older patients or those with low performance status"⁵⁵ leading to a lack of evidence, meaning that "treatment protocols are not optimised for the elderly."⁵⁶ Although upper age limits have largely been removed, criteria relating to fitness, frailty and prior treatments can often act as a barrier to entry⁵⁷.

Our survey found that older patients were less likely to be given the option of participating in a clinical trial (46% offered v 60%). This difference carried across all leukaemia types other than CML (43% offered 65+ v 44% offered U65) - ALL (55% v 79%), AML (57% v 71%), CLL (46% v 56%), other leukaemia (25% v 44%).

Investigating the reasons for patients joining clinical trials, older patients were more likely to do so because their consultant recommended it (61% v 49%) and more than twice as likely to join because there were no alternative treatment options (11% v 5%).

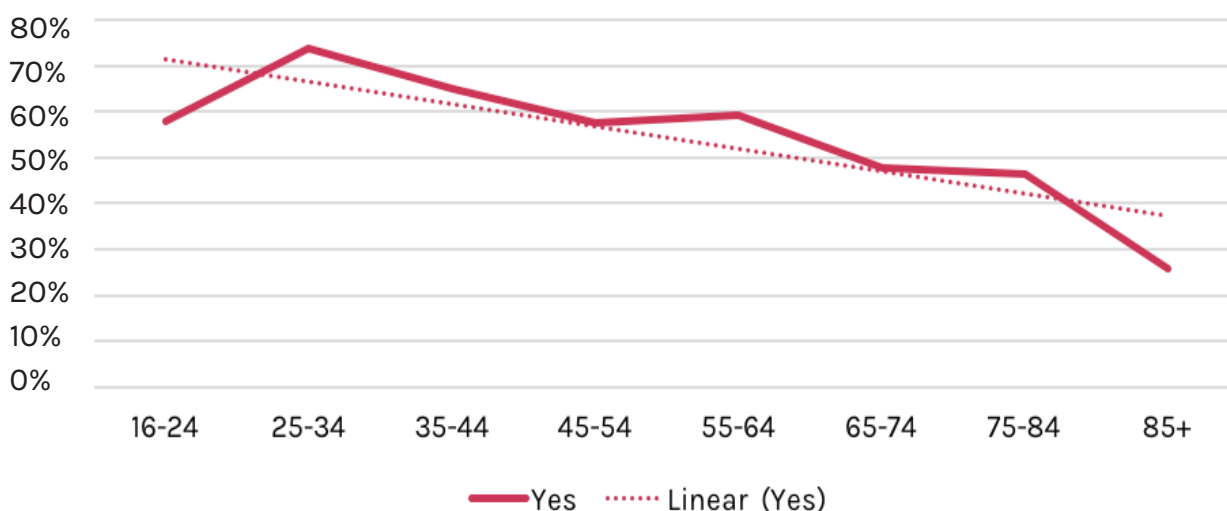
“I hope that trials in which I have participated will help other sufferers.”
CLL patient, (80-84)

Patients reasons for not joining the trial also varied. Older patients were more likely to be ineligible (32% v 27%), comment that the trial did not fit in with their 'day-to-day activities' (9% v 5%) or be unable to travel to the trial location (17% v 7%).

“I'm concerned about how far I have to travel.”
ALL patient, (80-84)

This resulted in a small difference between the number of patients who joined the trial when offered, with the number of patients joining the trial when offered was 85.6% in under 65s v 80.8% in those aged 65 and older.

Were you given the option of joining a clinical trial?



Symptoms

Interestingly, older patients were less likely to report symptoms at diagnosis, with 25% not experiencing (compared with 9%). Since their diagnosis, this evens out, with approximately 90% of patients in both groups experiencing symptoms of some kind. The most common symptoms amongst over 65s were fatigue (62%), feeling weak or breathless (37%), bruising and bleeding (36%) and sleeping problems (26%).

Financial

“As a consequence of my condition and the subsequent treatment, I made a decision to stop working and take early retirement.”
CML patient, (65-69)

As expected, 71% of patients over the age of 65 were not working before their diagnosis (compared to 13% of those aged under 65). Of those who were working, the over 65 group were less likely to have reported an impact on working hours (reducing hours or giving up work - 51% v 61%). Although, patients over the age of 65 were more likely to give up work altogether (rather than reduce hours).

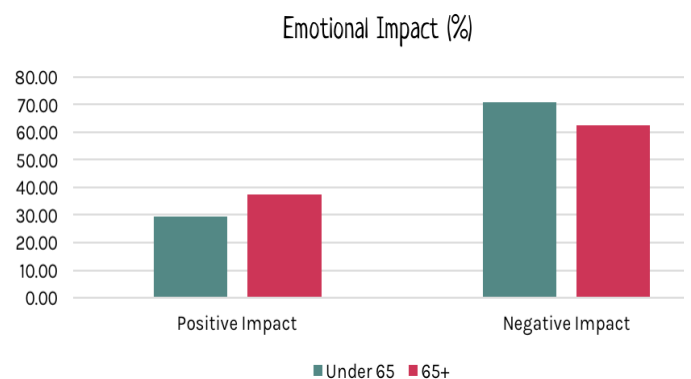
Looking at the impact on working hours by leukaemia type highlights a great deal of variation. Older patients were more likely to report an impact than their younger counterparts for ALL (71% v 50%), CLL (52% v 47%) and other leukaemia (48% v 17%). However, older patients were less likely to report an impact for AML (77% v 86%) and CML (44% v 58%).

“As I was retired at the time of diagnosis, there was no impact on my working life. However, there has been some financial impact on myself, which is that of trying to obtain a reasonable travel insurance. I own an old motorhome and also have friends who live in Spain, but the financial restrictions mean that I am not able to go abroad now as every price I was offered was over a £1000 for a 2-week period or they declined to cover me.”

CLL patient, (80-84)

Emotional



Additionally, patients aged 65 and over were significantly more likely to say that their emotional wellbeing had not changed since their diagnosis (51% v 28%). Of those who said that their emotional health had been affected, patients over 65 were more likely to report a positive impact (37% v 29%) than younger patients. For each leukaemia type, older patients were less likely to report feeling anxious or depressed, compared to their younger counterparts.








The 'Leukaemia: I wasn't born yesterday' report brings together findings from other sources, what we've heard from our supporters and the findings of the Leukaemia CARE cancer patient experience survey.

It highlights the challenges faced by leukaemia patients aged 65 and here we make ten recommendations for all stakeholders to consider as priority areas, in need of improvement.




Leukaemia Awareness

-  Improved awareness of leukaemia needed in people over the age of 65 and the link between incidence and increasing age
-  Improved awareness of the signs and symptoms of leukaemia, amongst the public and healthcare professionals who can aid earlier diagnosis (such as general practitioners)

Information and Support

-  All patients should receive written and verbal information about their condition and the different types of support available
-  This should include guidance on using the internet and verified websites for all ages
-  Patients should be given tailored information about their prognosis and treatment plan
-  Older patients should be asked if they are still working, so that employment related guidance can be provided to those who need it
-  Patients of all ages should have access to a Clinical Nurse Specialist (CNS) from their diagnosis onwards

Treatment

-  Treatment decisions must be made based on fitness, rather than chronological age
-  Patients of all ages should receive written information about Watch and Wait, to make sure that they fully understand the reasons for this
-  Patients of all ages should be given the option of joining clinical trials, so that the data provided is more representative of clinical practice

Unless otherwise stated, all internet links were last accessed in March 2017.

1. Cancer Research UK, Incidence Statistics, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>

2. Leukaemia CARE, Website, Acute Myeloid Leukaemia

<http://www.leukaemiacare.org.uk/acute-myeloid-leukaemia>

3. Leukaemia CARE, Website, Chronic Myeloid Leukaemia

<http://www.leukaemiacare.org.uk/chronic-myeloid-leukaemia>

4. Leukaemia CARE, Website, Acute Lymphoblastic Leukaemia

<http://www.leukaemiacare.org.uk/acute-lymphoblastic-leukaemia>

5. Leukaemia CARE, Website, Chronic Lymphocytic Leukaemia

<http://www.leukaemiacare.org.uk/chronic-lymphocytic-leukaemia>

6. Children with Cancer, Childhood Cancer Incidence Statistics (2001-2010)

<http://www.childrenwithcancer.org.uk/childhood-cancer-types>

7. Analysis of Cancer Research UK data, Incidence, Leukaemia, 0-19 years of age (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>

8. Analysis of Cancer Research UK data, Incidence, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>

9. Analysis of Cancer Research UK data, Incidence, All Cancer Types (2012-2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age>

10. Analysis of Cancer Research UK data, Incidence, Acute Lymphoblastic Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-all/incidence>

11. Cancer Research UK, Incidence, Acute Lymphoblastic Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-all/incidence>

12. Analysis of Cancer Research UK data, Incidence, Acute Lymphoblastic Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-all/incidence>

13. Cancer Research UK, Incidence, Acute Myeloid Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-aml/incidence>

14. Analysis of Cancer Research UK data, Incidence, Acute Myeloid Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-aml/incidence>

15. Cancer Research UK, Incidence, Chronic Lymphocytic Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-cll/incidence>

16. Analysis of Cancer Research UK data, Incidence, Chronic Lymphocytic Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-cll/incidence>

17. Cancer Research UK, Incidence, Chronic Myeloid Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-cml/incidence>

18. Analysis of Cancer Research UK data, Incidence, Chronic Myeloid Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia-cml/incidence>

19. Cancer Research UK, Incidence, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>

20. Analysis of Cancer Research UK data, Incidence, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>

21. National Cancer Intelligence Network (now National Cancer Registration and Analysis Service, part of Public Health England), Older People and Cancer, Version 3.0 (June 2015), pg. 15

http://www.ncin.org.uk/publications/older_people_and_cancer

22. Analysis of Cancer Research UK data, Mortality, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/mortality>

23. Analysis of Cancer Research UK data, Mortality, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/mortality>

24. Analysis of Cancer Research UK data, Incidence and Mortality, Leukaemia (2014)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia>

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/mortality>

25. Cancer Research UK, Cancer Survival by Age at Diagnosis (2009-2013)

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/survival>

26. De Angelis et al. Cancer survival in Europe 1999–2007 by country and age: results of EURO CARE-5-a population-based study. *Lancet Oncology* 2014; 15: 23-34

<https://www.ncbi.nlm.nih.gov/pubmed/24314615>

27. Sant et al, Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: results of EURO CARE-5, a population based study

<https://www.ncbi.nlm.nih.gov/pubmed/25030467>

28. Sant et al, Survival for haematological malignancies in Europe, pg. 931

<https://www.ncbi.nlm.nih.gov/pubmed/25030467>

29. Sant et al, Survival for haematological malignancies in Europe, pg. 935

<https://www.ncbi.nlm.nih.gov/pubmed/25030467>

30. Sant et al, Survival for haematological malignancies in Europe, pg. 939

<https://www.ncbi.nlm.nih.gov/pubmed/25030467>

- 31. Sant et al, Survival for haematological malignancies in Europe, pg. 931**
<https://www.ncbi.nlm.nih.gov/pubmed/25030467>
- 32. Sant et al, Survival for haematological malignancies in Europe, Figure 3, pg. 937**
<https://www.ncbi.nlm.nih.gov/pubmed/25030467>
- 33. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 34. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients, pg. 4**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 35. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients, pg. 4**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 36. Cancer Research UK, Leukaemia, Mortality (2014)**
<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/mortality>
- 37. Analysis of Sant et al, Survival for haematological malignancies in Europe. Estimate 914 lives saved if UK survival rates matched those in Northern Europe, of whom 743 would be over 65.**
<https://www.ncbi.nlm.nih.gov/pubmed/25030467>
- 38. Analysis of EUROCARE 5 data, applied to Cancer Research UK mortality leukaemia statistics. If UK survival matched Northern Europe.**
<https://www.ncbi.nlm.nih.gov/pubmed/25030467>
<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/mortality>
- 39. Cancer Patient Experience Survey, NHS England and Quality Health**
<https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>
- 40. Office for National Statistics, Internet users in the UK: 2016, Release 20 May 2016**
<https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016>
- 41. Cancer Research UK, Leukaemia, Diagnosis and Treatment Statistics**
<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/diagnosis-and-treatment#ref-2>
- 42. Cancer Patient Experience Survey 2014 – reported at Cancer Research UK, Leukaemia, Diagnosis and Treatment Statistics**
<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia/diagnosis-and-treatment#ref-2>
- 43. Independent Cancer Taskforce, Achieving World-Class Cancer Outcomes, A Strategy for England 2015-2020, Recommendation 61**
http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf
- 44. Cancer 52, Clinical Nurse Specialists working with people with rare and less common cancers (December 2016), pg. 3**
<http://www.cancer52.org.uk/wp-content/uploads/2017/01/CNS-FINAL-REPORT-Dec2016-Cancer52.pdf>
- 45. NCIN, Older People and Cancer, Version 3.0 (June 2015), pg. 30**
http://www.ncin.org.uk/publications/older_people_and_cancer

- 46. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 47. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients, page 4**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 48. NCIN, Older People and Cancer, Version 3.0 (June 2015), pg. 35**
http://www.ncin.org.uk/publications/older_people_and_cancer
- 49. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients, page 4**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 50. NCIN, Older People and Cancer, Version 3.0 (June 2015), pg. 5**
http://www.ncin.org.uk/publications/older_people_and_cancer
- 51. AM Brunner et al, Outcomes in patients age 70 or older undergoing allogeneic hematopoietic stem cell transplantation for hematologic malignancies. Biol Blood Marrow Transplant 2013 Sep;19(9):1374-80**
<https://www.ncbi.nlm.nih.gov/pubmed/23791626>
- 52. NCIN, Older People and Cancer, Version 3.0 (June 2015), pg. 6**
http://www.ncin.org.uk/publications/older_people_and_cancer
- 53. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients, page 4**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 54. Macmillan, Age old Excuse: The Under Treatment of Older Cancer Patients, pg. 14**
<http://www.macmillan.org.uk/documents/getinvolved/campaigns/ageoldexcuse/ageoldexcusereport-macmillancancersupport.pdf>
- 55. Sant et al, Survival for haematological malignancies in Europe, pg. 939**
<https://www.ncbi.nlm.nih.gov/pubmed/25030467>
- 56. Sant et al, Survival for haematological malignancies in Europe, pg. 939**
<https://www.ncbi.nlm.nih.gov/pubmed/25030467>
- 57. NCIN, Older People and Cancer, Version 3.0 (June 2015), pg. 57**
http://www.ncin.org.uk/publications/older_people_and_cancer



Leukaemia Care
YOUR Blood Cancer Charity