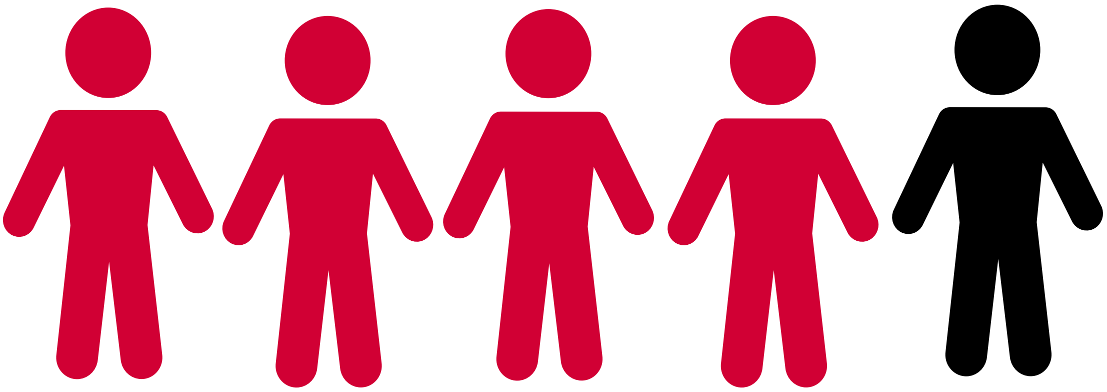
Leukaemia CARE:
Living with Leukaemia

A survey of 2,019 leukaemia patients



4 in 5

83% did not suspect cancer before their diagnosis

Blood and Lymphatic cancers
Leukaemia CARE
supporting a quality of life

Contents

1. Executive summary

Over 9,500 people are diagnosed with leukaemia in the UK every year, meaning leukaemia is the 12th most common cancer diagnosed in the UK.[1]

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. In most cases of leukaemia there is no obvious cause.

There are a number of different types of leukaemia, but the four most common are:
Acute myeloid leukaemia (AML) – Rapidly developing, affects myeloid cells (granulocytes)
Chronic myeloid leukaemia (CML) – Slowly developing, affects myeloid cells (granulocytes)
Acute lymphoblastic leukaemia (ALL) – Rapidly developing, affects lymphocytes
Chronic lymphocytic leukaemia (CLL) – Slowly developing, affects lymphocytes

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.

Each year NHS England commission a national cancer patient experience survey (CPES). However, whilst there are similarities and common challenges, we often hear from leukaemia patients that their experiences are very different from other cancer types. Leukaemia CARE appointed Quality Health to undertake a survey of individuals who had received a leukaemia diagnosis. The aim was to gather data on patient's experiences of their diagnosis, care and treatment journey, quality of life, access to information/support and views on potential new treatments. This was done to build on the evidence available through the CPES survey, identifying issues that are specific to leukaemia.

Leukaemia CARE's follow-on survey was sent to 1711 leukaemia patients identified using the National Cancer Patient Experience 2015 Survey, and who had consented to be contacted again. There were 1320 responses received, resulting in a response rate of 78%.

In addition, an anonymous online survey of the wider blood cancer community was also run and publicised by blood cancer charities through various online and print channels. 1199 people completed the online questionnaire, of which 699 identified themselves as leukaemia patients.

The main profile of the leukaemia respondents was as follows:

65% came from CPES and 35% were from the anonymous cohort
57% were male, 43% were female
Over half of the respondents (59%) were aged between 55 and 74; 16% were aged between 75 and 84; and 3% were aged over 85; 13% were aged 45 to 54; and 9% were under the age of 44

The results from the survey have created a robust dataset, covering a number of themes. The data has revealed differing aspects of patient experience in relation to the variables present within leukaemia patients, and draws attention to areas where further policy and campaigning work should be undertaken.

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[1] http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero

These areas are listed below.

Awareness of leukaemia as an aid to earlier diagnosis

Leukaemia (as a term) is well known, with 83% of patients reporting that they had heard of it before their diagnosis. However, there is little public understanding of leukaemia, with only a third of these patients reporting that they knew anything about it.

Recommendation 1: There is a need for greater public knowledge of leukaemia. That leukaemia is a cancer of the blood, that can affect people of all ages.

There are numerous signs and symptoms associated with leukaemia but they also are notoriously vague and non-specific. Although a doctor may suspect a patient has leukaemia based on signs and symptoms it can only be diagnosed by laboratory tests.

The most common symptoms reported before diagnosis were fatigue, bleeding or bruising, bone or joint pain, fever or night sweats, sleeping problems and shortness of breath.

Additionally, despite most patients (81%) experiencing symptoms before their diagnosis, very few people expected (3%) or suspected (14%) that they may have cancer. This suggests that people are not aware of the symptoms that could indicate a potential leukaemia. As a result, 44% of acute leukaemia patients and 66% of chronic leukaemia patients said they waited over a month before going to see their GP. On average 1 in 5 (22%) leukaemia patients said they visited their GP more than 3 times before they were referred to hospital.

Our results show that there are big differences between the four main types of leukaemia in the reported route to diagnosis, but overall an emergency presentation was the most common route. In addition, there should be concerns that overall 13% (ranging between 8% and 24% across the different leukaemia types), were initially treated by their GP for another condition. Less than half (44%) of respondents felt their GP had a complete understanding of blood cancers.

Recommendation 2: There needs to be an overall improvement of awareness for the signs and symptoms of leukaemia, amongst both the public and the healthcare professionals who can aid in earlier diagnosis (such as general practitioners).

Different types of leukaemia

Whilst some aspects of patient experience are common to all leukaemia types, our results show a number of significant differences between the different types of leukaemia. The most pronounced differences are between acute leukaemia and chronic leukaemia patients. For example, route to diagnosis, being unaccompanied to the diagnosis meeting, impact on work or education, provision of additional support and provision of a Clinical Nurse Specialist.

Recommendation 3: Provision of support and information should be given on a tailored basis, to recognise the different needs of patients with different types of leukaemia.

Understanding of leukaemia diagnosis

On average, only half of all leukaemia patients fully understood the explanation of what was wrong with them, 44% only had a partial understanding and 6% did not understand the explanation at all. Those from the anonymous online cohort of patients were much less likely to say they understood the information, suggesting that this may be a reason that they contact charities for additional information/support.

Recommendation 4: The information and explanation given at diagnosis needs to be improved, to ensure leukaemia patients fully understand what is wrong with them. This should incorporate the provision of written materials at each stage of their journey.

'Watch and wait'

The survey confirmed many points about 'watch and wait' that patients had raised with us anecdotally. Primarily this focuses on CLL, with over three-quarters (77%) of CLL patients in our sample having been placed on 'watch and wait'. Almost all patients with CML or with acute leukaemia will start treatment soon after diagnosis. However, there were a small number of non-CLL leukaemia patients that said they were placed into active monitoring.

The majority of people (92%) said they understood the reasons for being placed on 'watch and wait', but over half (54%) either had some concerns and worries (42%) or were very worried (12%). Of those who wanted written information about 'watch and wait', 56% were given it and found it to be understandable, a third were not given any written information and a further 8% were given information but found it difficult to understand.

Our results show there is a direct correlation between the amount of written information given, how easy it is to understand and to how worried a patient feels. Patients not given any information were 4 times more likely to be very concerned and worried about being put on 'watch and wait'. In addition, those who said they received information, but that it was difficult to understand were nearly 6 times more likely to be very concerned/worried than those who found the information easy to understand, and 1.5 times more likely than those who were not given any information. Overall, the patients who were most worried were those who received information but found it difficult to understand.

Recommendation 5: Leukaemia patients placed on 'watch and wait' should receive a full and understandable explanation about what this means, and this should also include the provision of written information specifically about 'watch and wait'.

Clinical Trials

Across all types of leukaemia 50% of respondents said they were not given the opportunity to join a trial, although within these responses there was variation between leukaemia types. When people were offered the opportunity to enter a trial, 82% went on to join. There is a clear missed opportunity here for more people to access new and innovative therapies, treatments and regimes which would not otherwise be available on the NHS. Similarly, failure to recruit more people on to trials hinders progress and advances in clinical and observational research. In addition to this, our survey confirms that older patients are less likely to be given the opportunity to join a clinical trial: 46% of those 65 and over were given the option, compared to 55% of those under 65.

Recommendation 6: Where appropriate, health professionals should speak to leukaemia patients about the option to participate in clinical trials, regardless of the age of the patient.

Living with Leukaemia

Our survey findings also show a wide range of physical impacts on leukaemia patients. For example, just over half of patients (51%) reported experiencing pain as a result of their condition. Additionally, 43% reported that it had impacted on their mobility, highest in the ALL group (61%). Acute leukaemia patients also reported it impacting on their ability to perform daily routines, such as cooking or cleaning (65% ALL, 59% AML).

One of the areas we were interested to understand, was patients' day-to-day experiences of living with leukaemia. One of the most important areas for leukaemia patients is the impact of their cancer on finances. On average 40% of people reported experiencing a negative impact on their finances, but this ranges between 32% and 60% across the different leukaemia types. Considering that only 55% of leukaemia patients from 2015 CPES said that hospital staff gave them information about how to get financial help or benefits they might be entitled to, this suggests that many patients are not receiving valuable help and advice.

Recommendation 7: The support and advice given by hospitals about the financial impact of leukaemia needs to be improved, incorporating signposting to organisations who offer specialised financial support.

The Internet

Our findings clearly show that there are a variety of different reasons leukaemia patients reach out for support. In addition, the method of support or information desired is different for every patient.

The internet can be a valuable resource, with the NHS stretched to provide time for patients, charity websites can be an excellent source of information and support for people. However, our survey revealed two-thirds of patients weren't told anything about the internet by their health professional, even though 61% had used it to find further information. Those who had spoken with their health professional, and had been advised to look at trusted websites were more likely to find the information useful.

Recommendation 8: When discussing support with leukaemia patients, health professionals should give guidance on using the internet and direct patients to verified websites.

Emotional Impact

The emotional impact of a cancer diagnosis should not be underestimated. Leukaemia patients will be challenged in different ways, whether an acute patient dealing with an aggressive illness and invasive treatments, or a chronic patient living with the knowledge they have an incurable disease. There is also the possibility that a patient may relapse, and our research has shown that this has a clear impact on their emotional well-being. Disappointingly, the survey showed that on average only 16% of patients said they were offered counselling or psychotherapy, ranging from 34% down to 8% across the different types, with chronic patients much less likely to say they were offered it compared to their acute counterparts.

Recommendation 9: More consideration should be taken for the psychological and emotional needs of patients, with signposting to appropriate services, and in particular for those on 'watch and wait' and for those who have relapsed.

Clinical Nurse Specialists

The survey findings challenge the data available for the provision of Clinical Nurse Specialists (CNSs) to leukaemia patients. 85% of 2015 CPES leukaemia patients said they had been given the name of a CNS, but on average only 38% of the people we surveyed said they had been given access to a CNS. This was even lower for those with a chronic leukaemia and those on ‘watch and wait’. There is a clear gap where patients are living with a chronic disease, not in active treatment and are missing the opportunity to access a CNS. As it is widely accepted that the presence of a CNS is one of the most powerful positive influences on a patient’s cancer experience, it is imperative that they are made available to all leukaemia patients.

Recommendation 10: The provision of CNSs across all leukaemia types needs to be increased, including patients with a chronic form of leukaemia and those still on ‘watch and wait’.

2. Background and methodology

2.1 Background and objectives

This project was designed as a follow up to NHS England’s annual Cancer Patient Experience Survey (CPES). It aimed to provide further evidence on leukaemia patient experience, with a focus on the varying needs of patients with different forms of leukaemia.

It was designed to explore and quantify the issues being reported to Leukaemia CARE by individual patients, to provide a broader picture of how these issues are affecting other patients. However, through asking wider questions on patient experience it also sought to identify issues that Leukaemia CARE were unaware of, or unaware of the extent of.
Through exploring two distinct cohorts (those who had previously responded to CPES and those recruited via charities to an anonymous online link) the project seeks to identify areas where leukaemia patients reach out to charities for support, as well as areas that patients need support but currently have nowhere to reach out to.

In addition, Leukaemia CARE believes it has a responsibility to ensure that when representing patients in external activities all patients are being represented, even if they choose not to reach out to the charity for support. Through reaching out to CPES patients who had not received support from charities, the project seeks to ensure that their views are appropriately included in Leukaemia CARE’s work to drive improvements in patient experience, through the delivery of services and campaigns for external improvements.

2.2 Questionnaire design and development

The questionnaire was developed and designed over a number of months in 2016, following detailed discussion between Leukaemia CARE and Quality Health. Once the question set was agreed, the questionnaire was tested by 9 volunteers who were willing to fill it in; and then discuss their thoughts on various aspects of the questionnaire design. This included comments on the questions and their wording; whether the answer options accurately reflected their experiences; whether there was anything missing; and on whether the page layout was easy to follow. This exercise contributed towards refining the questionnaire into a finished version.

The online version of the questionnaire included 7 additional questions and 2 questions with additional answer options; in order to capture respondent characteristic data already collected/known from the CPES cohort.

2.2.1 Sampling and National Cancer Patient Experience Survey data

This piece of research is centred on the specific experiences of men and women with a blood cancer, with a particular focus on leukaemia.

The project was carried out using 2 arms of data collection.
Arm 1: Contacting Leukaemia patients identified using National Cancer Patient Experience 2015 Survey data (CPES) – those who had agreed to be contacted again/
Arm 2: An anonymous online survey of the wider blood cancer community – using an extended question set – and publicised through various online and print channels, run throughout the period of Arm 1.

For Arm 1, the sample was drawn using CPES data from 2015. Each of the individuals in the sample had given permission to be contacted again with a further survey – which is one of the questions in the CPES.

ICD10 codes were used to identify the cohort of patients required. The sample included all people with leukaemia by using the following ICD10 codes.

ICD-10 Four Character Sub-Category Code	Tumour Grouping	ICD-10 Description
C901	Haematological	C90 Plasma cell leukaemia
C910	Haematological	C91 Acute lymphoblastic leukaemia [ALL]
C911	Haematological	C91 Chronic lymphocytic leukaemia of B-cell type
C913	Haematological	C91 Prolymphocytic leukaemia of B-cell type
C914	Haematological	C91 Hairy-cell leukaemia
C915	Haematological	C91 Adult T-cell lymphoma/leukaemia [HTLV-1-associated]
C916	Haematological	C91 Prolymphocytic leukaemia of T-cell type
C917	Haematological	C91 Other lymphoid leukaemia
C919	Haematological	C91 Lymphoid leukaemia, unspecified
C920	Haematological	C92 Acute myeloblastic leukaemia [AML]
C921	Haematological	C92 Chronic myeloid leukaemia [CML], BCR/ABL-positive
C922	Haematological	C92 Atypical chronic myeloid leukaemia, BCR/ABL-negative
C924	Haematological	C92 Acute promyelocytic leukaemia [PML]
C925	Haematological	C92 Acute myelomonocytic leukaemia
C928	Haematological	C92 Acute myeloid leukaemia with multilineage dysplasia
C929	Haematological	C92 Myeloid leukaemia, unspecified
C930	Haematological	C93 Acute monoblastic/monocytic leukaemia
C931	Haematological	C93 Chronic myelomonocytic leukaemia
C940	Haematological	C94 Acute erythroid leukaemia

C944	Haematological	C94 Acute panmyelosis with myelofibrosis
C950	Haematological	C95 Acute leukaemia of unspecified cell type
C951	Haematological	C95 Chronic leukaemia of unspecified cell type
C959	Haematological	C95 Leukaemia, unspecified

When drawing the sample, Quality Health carried out death checks to ensure that no questionnaire was sent to any person who had since died, and the sample was checked to ensure that no duplication took place – so no one received more than one questionnaire.
At the same time as Arm 1 was underway, an online survey targeting people with any type of blood cancer and using an extended question set – was launched. Leukaemia CARE undertook a publicity campaign to promote the survey.

The survey link was promoted by Leukaemia CARE through its social media, magazine and email distribution lists. Additionally, a hard copy version was sent out to support group members, to ensure the sample was representative.

We would also like to thank ACLT, Anthony Nolan, Basil Skyers Myeloma Foundation, Bloodwise, CLL Support Association, CML Support, Lymphoma Association, MDS UK, MPN Voice, Myeloma UK and WMUK for their help in sharing the survey with their memberships.

This report will use all data from Arm 1 along with respondents from Arm 2 stating they had a confirmed diagnosis of leukaemia.

A detailed analysis of the survey results was carried out paying particular attention to any differences between the data sets. We have summarised these differences in detail in section Appendix 1, and have made reference to these throughout section 3, where this is appropriate and where differences are most pronounced.

2.3 Timescales and fieldwork

The questionnaire was agreed in August 2016. The send out by post consisted of an initial mailing with a covering letter; a reminder letter; and finally, another reminder letter, with a further copy of the questionnaire included. Only people who had not yet returned their questionnaire were sent a reminder. Questionnaires were sent back to Quality Health in a pre-paid reply envelope, however the respondents were also able to complete the questionnaire online, or over the phone if they preferred and there were helpline and language line facilities available through the course of the send out.

Arm 1 send out took place on 26 September 2016, with reminders following on 17 October and 8 November. The field work closed on 16 December 2016.

Arm 2 was launched at the same time as Phase 1, and was open for completion until 16 December 2016.

2.4 Response rate

The response rates for each of the phases of the survey were as follows:

Arm	Responses received	Response rate
1	1320	78%
2	1199	-
TOTAL	**2519**	

Arm 1 – Questionnaires were sent to 1711 CPES respondents. 28 were excluded for the following reasons:

Moved / not known at this address	5
Deceased	23

Method of questionnaire completion for Arm 1 was as follows:

Paper questionnaire	1196
Online	107
Telephone completion	1
Language line completion	16

Both Arms combined saw 2519 completed questionnaires.

The number of leukaemia respondents were as follows:

Arm 1 (CPES)	1320
Arm 2 (anonymous)	699
TOTAL	**2019**

3. Results of the questionnaire

3.1 Respondent characteristics

3.1.1 Gender

Overall, 57% of respondents were male and 43% were female.

The split between male and female from CPES respondents was weighted towards more male participants - 63% male and 37% female. The online respondents contained more females - 45% male 55% female. These results suggest that despite leukaemia being more prevalent in males, it is females that are more likely to seek support for their condition.

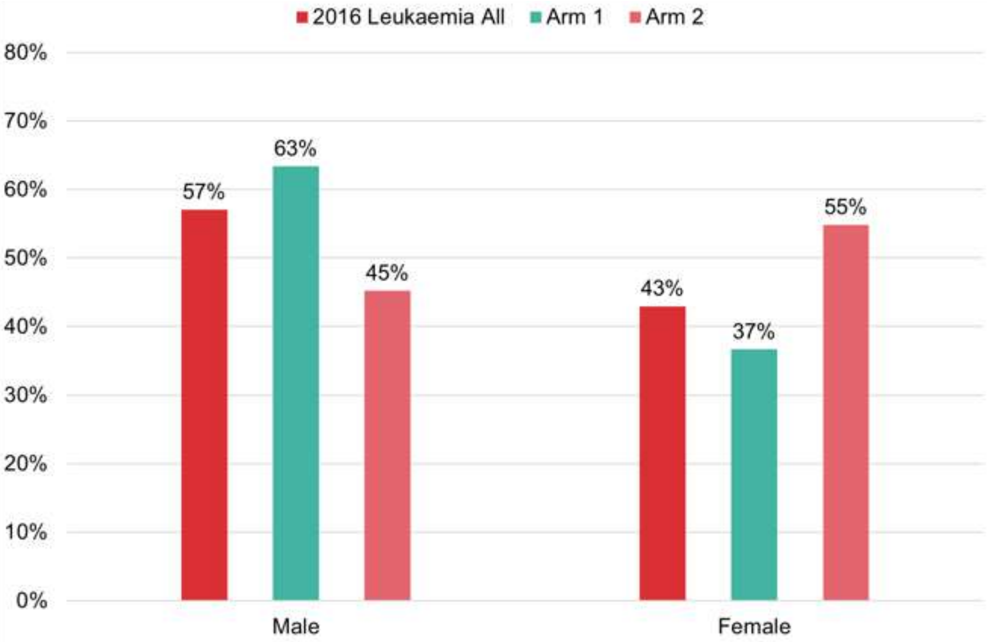


Figure 1: Distribution of respondents by gender

3.1.2 Age

Overall, 9% of respondents were aged between 16 and 44; 38% were aged between 45 and 64; and 54% were aged 65 or over.

Younger respondents were more likely to have been recruited into the survey through Arm 2, Leukaemia CARE and its' associated partners. Older respondents were more likely to have been contacted via Arm 1, CPES.

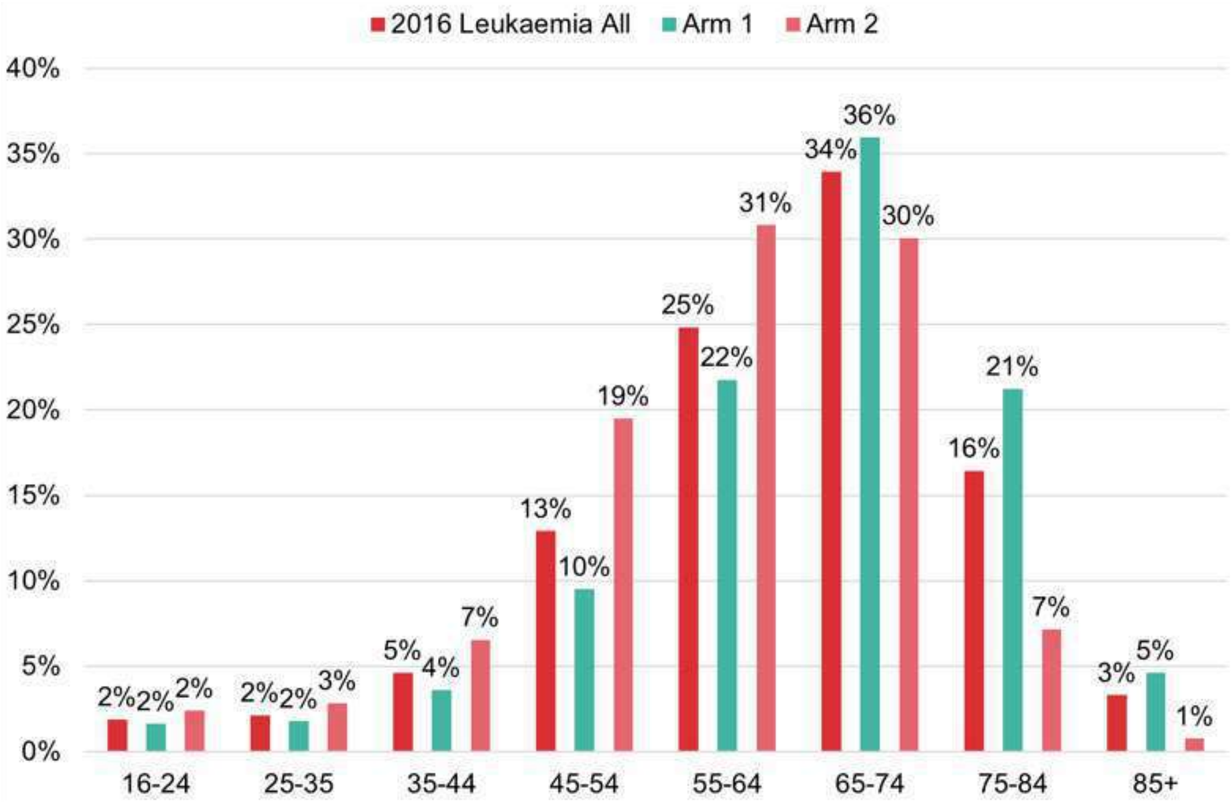


Figure 2: Distribution of respondents by age band and patient cohort

As may be expected, the age profile of respondents varies for each type of leukaemia, as the chart below demonstrates:

	16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
■ 2016 Leukaemia All	2%	2%	5%	13%	25%	34%	16%	3%
■ ALL	15%	15%	12%	25%	15%	12%	6%	0%
■ AML	2%	2%	5%	18%	29%	30%	12%	2%
■ CLL	0%	0%	1%	6%	24%	41%	22%	5%
■ CML	3%	3%	11%	20%	26%	25%	10%	1%
■ All other leukaemia	0%	3%	8%	20%	23%	32%	11%	2%

Figure 3: Distribution of respondents by age band and leukaemia type

3.1.3 Ethnicity

94% of respondents identified as being white British, 4% as black or another minority ethnic group (BME) and 2% did not provide this information. These demographics are not dissimilar to the National Cancer Patient Experience 2015 Survey, where 89% identified as white British, 4% as BME and 6% did not provide information.

3.1.4 Diagnosis

This report focuses on the experiences of the leukaemia patients surveyed.

This includes all participants from Arm 1 and selected participants from Arm 2.

Arm 1 contained 1320 Leukaemia patients identified using National Cancer Patient Experience 2015 Survey data – the diagnosis is ‘physician reported’.

Participants in Arm 2 were asked "What was your confirmed diagnosis?" and permitted to tick all that applied to them from a comprehensive list of blood cancers – the diagnosis is ‘patient reported’. Only those who selected a type of leukaemia and no other type of blood cancer have been included in the report.

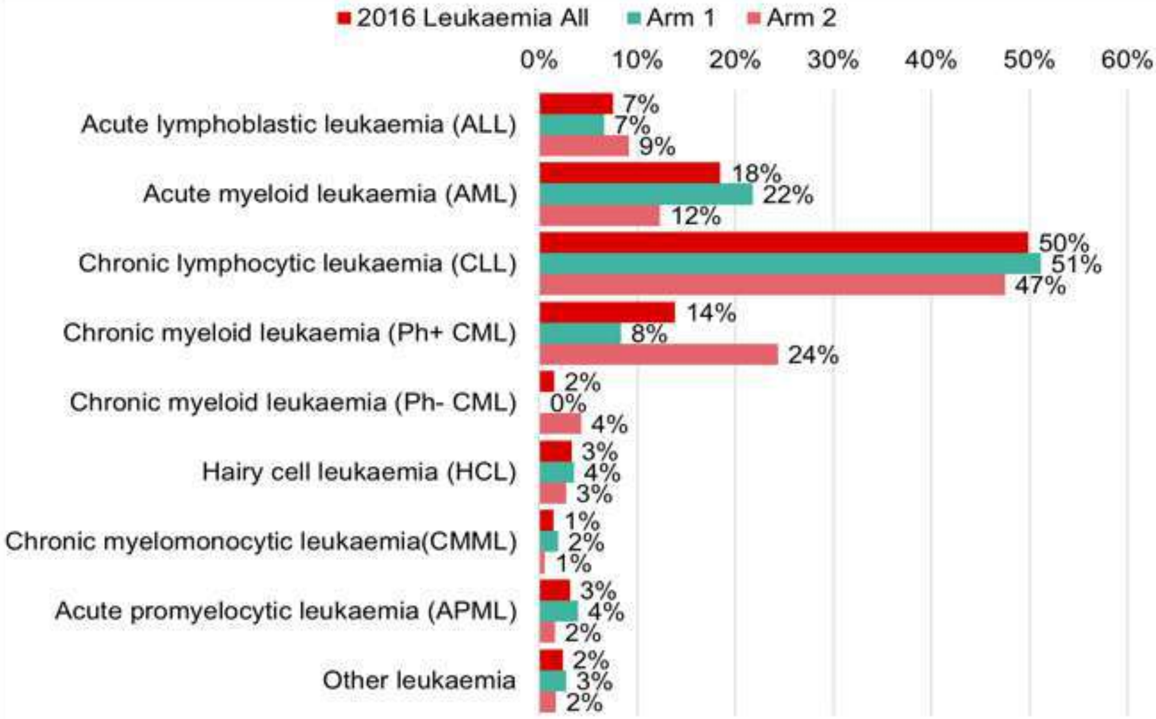


Figure 4: Distribution by leukaemia type

Interestingly the patient reported method of collecting diagnosis revealed that some respondents do not have a full understanding of their diagnosis. It was noted to be unlikely that so many CML patients from Arm 2 would be PH-, further analysis showed that 65% of respondents that selected CML PH- had selected both PH+ and PH-, and the associated comments explained that they did not know what type of CML they had.

"I didn’t know there was a plus or minus CML." – [CML, 45-54]

"Was only told I had CML not if it was plus or minus." – [CML, 55-64]

"I am not sure which type of CML I was diagnosed." – [CML, 25-34]

3.1.5 Location

The tables below show the location of respondents. For Arm 1 this was collated from CPES data and grouped into strategic clinical network areas. For Arm 2 respondents were asked where they lived by UK country or non-UK country.

Strategic Clinical Network	
Cheshire and Mersey	41
East Midlands	151
East of England	118
Greater Manchester, Lancashire and South Cumbria	83
London	215
Northern	69
South East Coast	134
South West	124
Thames Valley	48
Wessex	60
West Midlands	139
Yorkshire and The Humber	138
Total	**1,320**

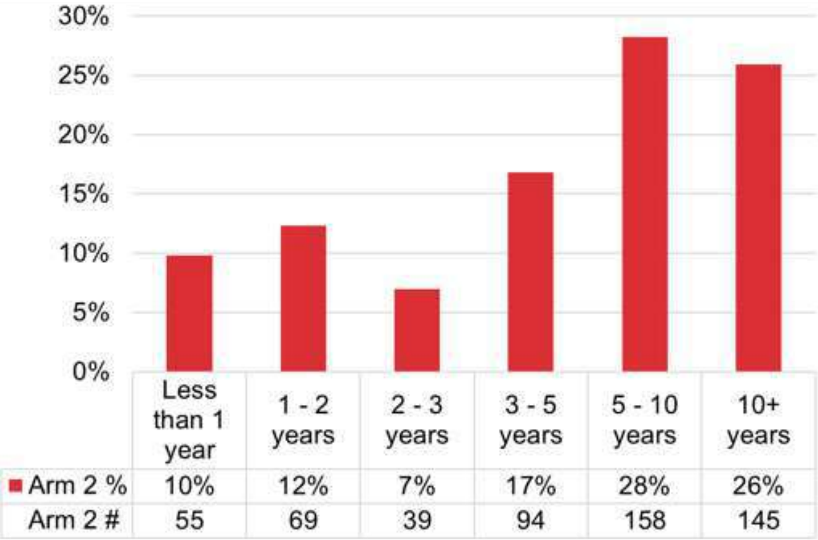
Figure 5: Distribution of respondents from Arm 1 by Strategic Clinical Network

Country	
England	1892
Northern Ireland	14
Scotland	57
Wales	41
Non-UK	9
Missing	6
Total	**2,019**

Figure 6: Distribution of respondents from Arm 2 by country

3.1.6 Time since diagnosis

Respondents from Arm 2 were asked to give the year of their diagnosis, of those who gave this information, over half were diagnosed more than 5 years ago.

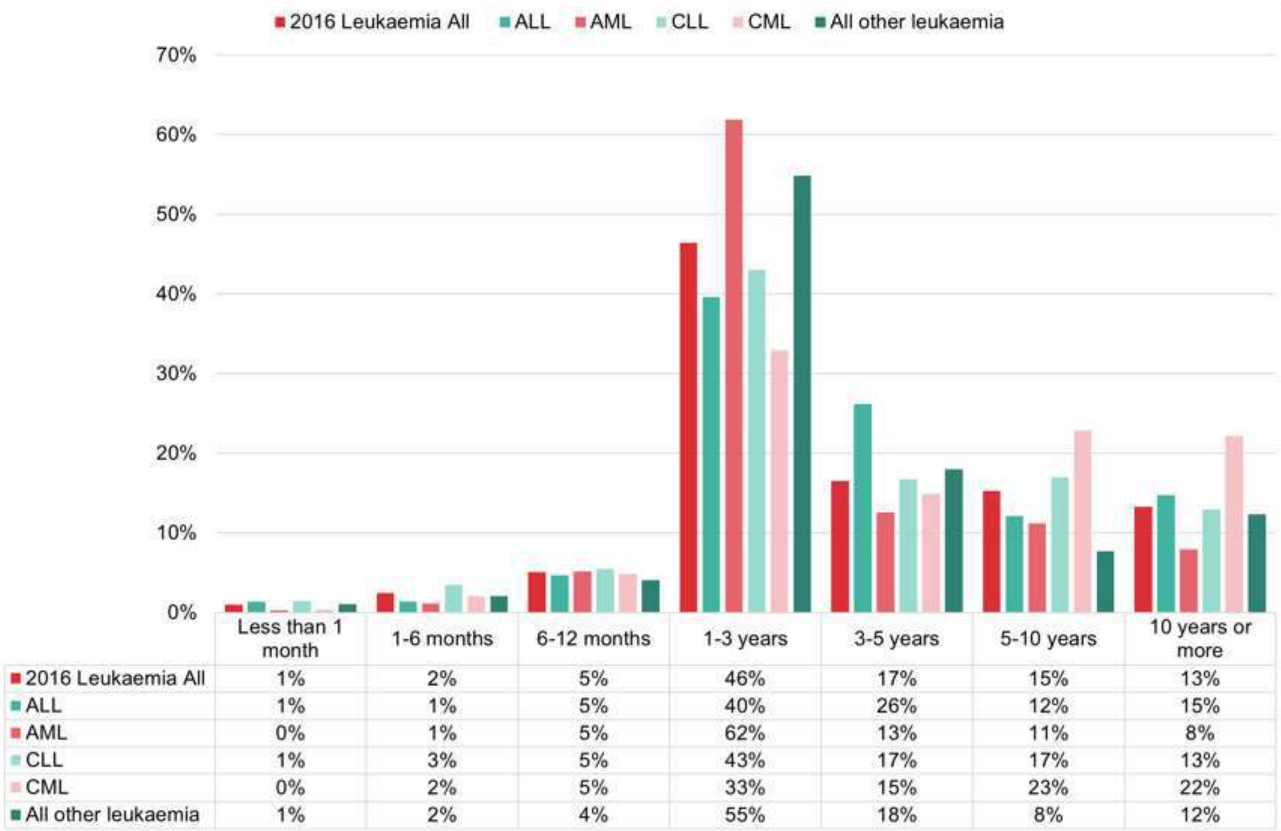


	Less than 1 year	1 - 2 years	2 - 3 years	3 - 5 years	5 - 10 years	10+ years
■ Arm 2 %	10%	12%	7%	17%	28%	26%
Arm 2 #	55	69	39	94	158	145

Figure 7: Arm 2 time since diagnosis

3.1.7 Time since first started treatment

The chart below illustrates the spread of responses for the time it had been since patients first started treatment. For all leukaemia types the most common answer was between 1-3 years.



	Less than 1 month	1-6 months	6-12 months	1-3 years	3-5 years	5-10 years	10 years or more
■ 2016 Leukaemia All	1%	2%	5%	46%	17%	15%	13%
■ ALL	1%	1%	5%	40%	26%	12%	15%
■ AML	0%	1%	5%	62%	13%	11%	8%
■ CLL	1%	3%	5%	43%	17%	17%	13%
■ CML	0%	2%	5%	33%	15%	23%	22%
■ All other leukaemia	1%	2%	4%	55%	18%	8%	12%

Figure 8: Time since first started treatment

3.1.8 Time in remission/response since first/original treatment

What has been the length of time in remission or response from your first/ original treatment?	ALL	AML	CLL	CML	All other leukaemia	2016 Leukaemia All
Not in remission or response	3%	4%	6%	9%	5%	6%
Treatment or remission ongoing	25%	21%	24%	44%	19%	26%
0-6 months	4%	6%	5%	3%	7%	5%
6-12 months	5%	11%	11%	5%	8%	9%
1-2 years	14%	34%	17%	11%	22%	20%
2-3 years	15%	10%	7%	6%	13%	8%
3-5 years	20%	9%	10%	6%	12%	10%
5-10 years	7%	8%	6%	11%	6%	7%
10 years or more	12%	6%	4%	13%	8%	6%
Palliative care	0%	3%	1%	1%	0%	1%
Not applicable	1%	1%	17%	3%	6%	10%

Figure 9: Time in remission/response since first/original treatment

3.2 Before diagnosis

The following questions looked at respondents' experiences before their diagnosis, including the symptoms they experienced before diagnosis, whether they thought their GP had a good understanding of leukaemia and their route to being diagnosed.

3.2.1 Symptoms experienced

Blood cancers may cause numerous different symptoms. We asked what symptoms respondents experienced before their diagnosis for leukaemia, and also asked them to select all that applied.

The most frequently experienced symptom was fatigue 55%, followed by feeling weak or breathless 37% and then fever / night sweats 28%. 19% of respondents encountered no symptoms prior to their diagnosis.

The chart below shows the full range of replies:

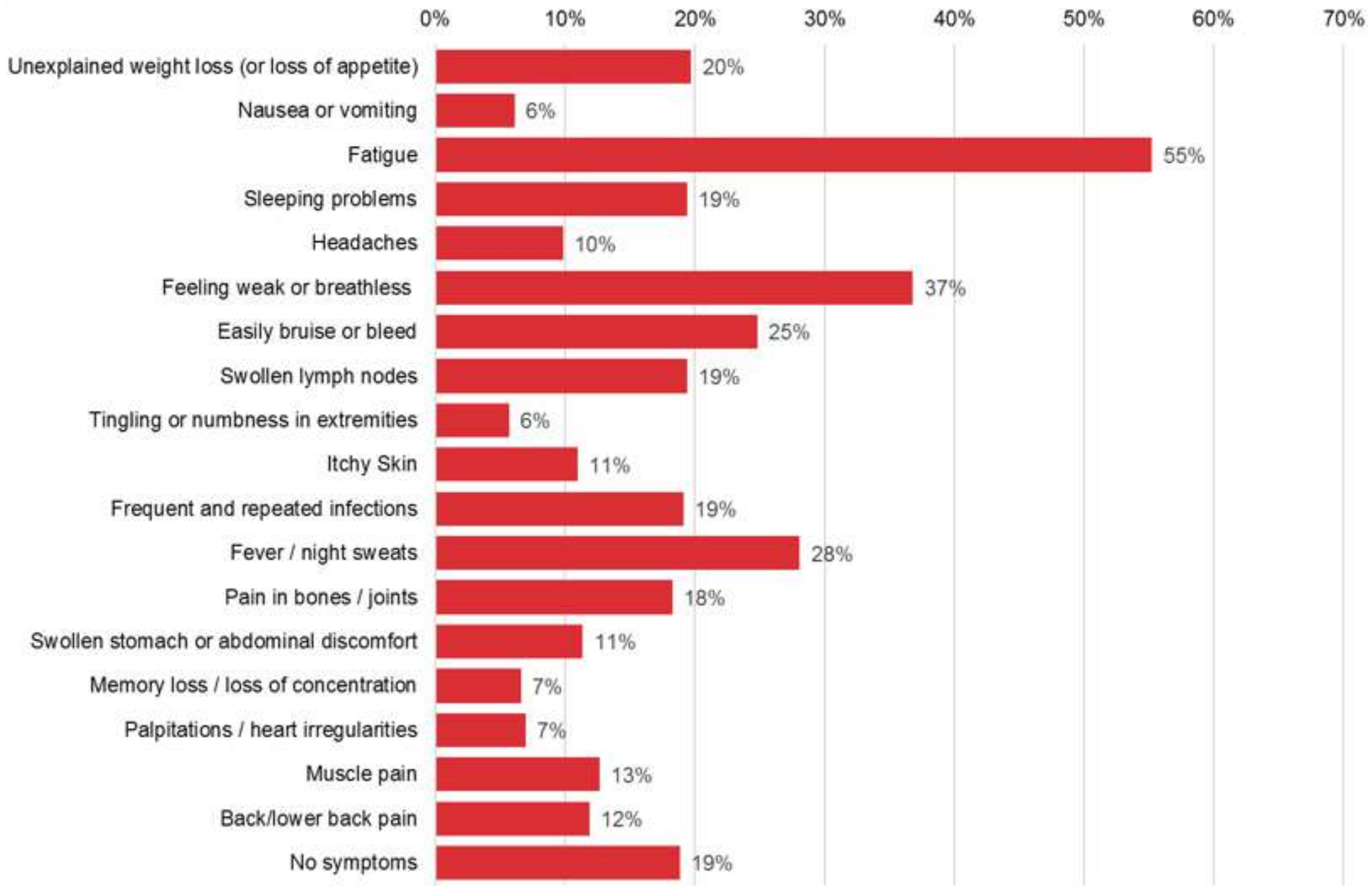


Figure 10: Symptoms experienced prior to diagnosis

The top five most reported symptoms for each leukaemia type are as follows:

ALL
Fatigue **69%**
Feeling weak or breathless **61%**
Fever / night sweats **36%**
Easily bruise or bleed **31%**
Pain in bones / joints **28%**

CLL
Fatigue **43%**
Swollen lymph nodes **31%**
No symptoms **28%**
Feeling weak or breathless **24%**
Fever / night sweats **24%**

Other Leukaemia
Fatigue **59%**
Easily bruise or bleed **50%**
Feeling weak or breathless **44%**
Fever / night sweats **29%**
Frequent and repeated infections **22%**

AML
Fatigue **70%**
Feeling weak or breathless **56%**
Easily bruise or bleed **31%**
Fever / night sweats **26%**
Pain in bones / joints **24%**

CML (PH+ & PH-)
Fatigue **68%**
Fever / night sweats **41%**
Unexplained weight loss (or loss of appetite) **40%**
Feeling weak or breathless **40%**
Easily bruise or bleed **30%**

3.2.2 GPs' understanding of blood cancers

The following chart shows the percentage of respondents who felt their GP had a good understanding of blood cancers. 44% of respondents felt their GP had a complete understanding of blood cancers, with 19% feeling their GP did not know about blood cancers at all. These results are understandable when you consider the generalist knowledge of primary care, combined with the relative rarity of blood cancers and the vague and non-specific symptoms they often present with (e.g. fatigue). This illustrates the difficulties for patients and GPs in identifying blood cancers. Leukaemia CARE understands that the role of the GP in the early diagnosis of blood cancers is crucial, so have developed two online learning modules, in partnership with the Royal College of General Practitioners eLearning team, to aid early diagnosis of blood cancers and support ongoing professional development. For more information on the modules, see http://www.leukaemiacare.org.uk/GP-training

"My GP was hopeless when I initially went to them with my health problems. If they had sent me for a blood test earlier, my blood cell count would not have been dangerously low. It took many visits to GP over a month until they did a blood test. GP's should know more about leukaemia. My symptoms were classic for this condition." – [CLL patient, 65-74]

"the GP could have spotted the symptoms quicker." – [CML patient, 35-44]

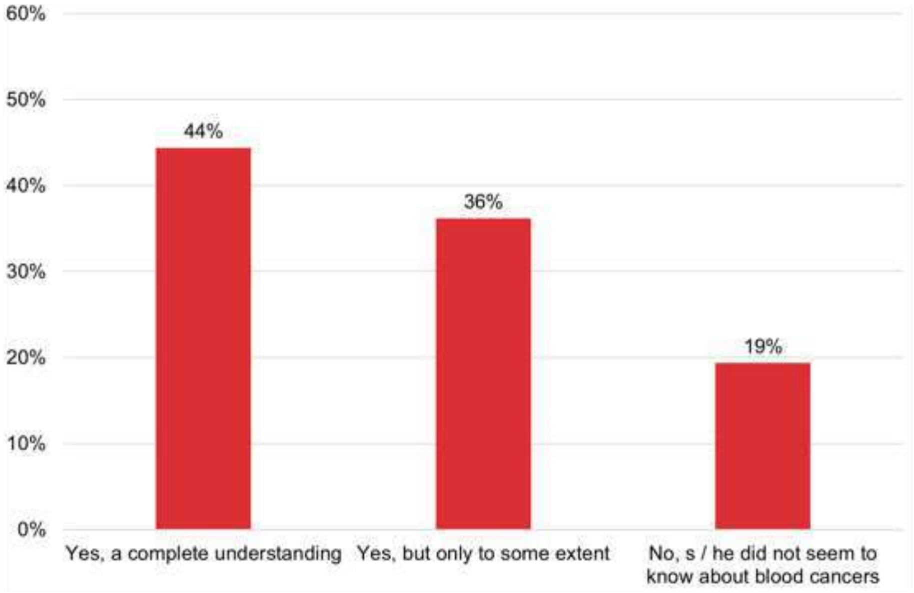


Figure 11: GP's understanding of blood cancers

3.2.3 Route to diagnosis

We asked respondents to explain their initial route to being diagnosed with a blood cancer. The results below illustrate the variety that is still present in patients' route to diagnosis, in particular depending on the type of leukaemia.

- Patients with an acute leukaemia are more likely to be sent straight to hospital on the same day, or be seen as an emergency or A&E patient
- Patients with a chronic leukaemia are more likely to be seen via an urgent referral (two-week wait)
- CLL patients are more likely to have been seen via a non-urgent referral
  Patients with an acute leukaemia are more likely to have been initially treated for another condition

In addition, respondents reporting swollen lymph nodes, swollen stomach/abdominal discomfort, unexplained weight loss or those who were asymptomatic were more likely to be given an urgent referral. Also, those respondents who experienced palpitations/heart irregularities, nausea/vomiting and headaches were more likely to say they were initially treated for another condition.

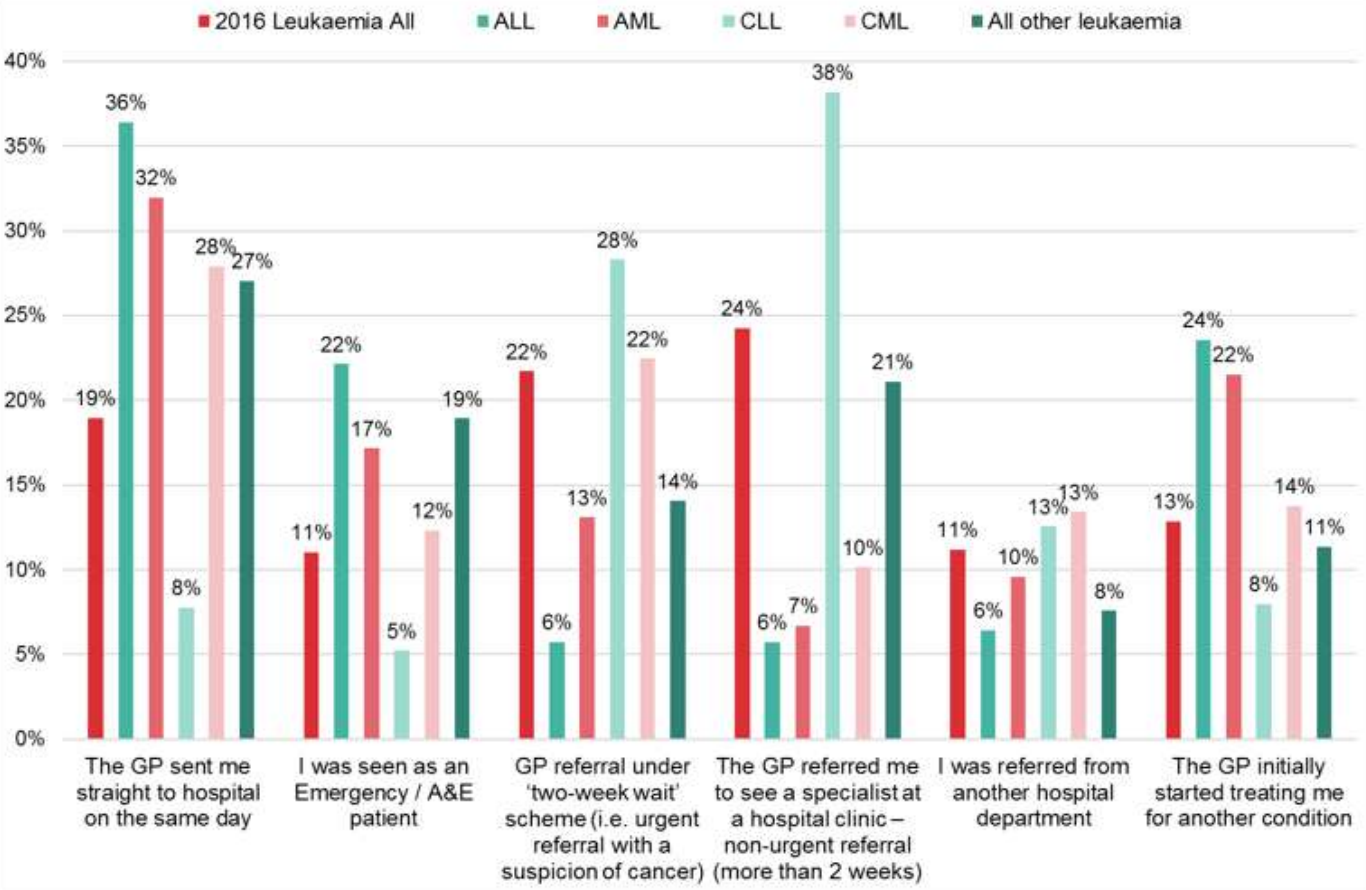


Figure 12: Route to diagnosis - by leukaemia type

Younger respondents were more likely to have been admitted as an emergency/A&E patient. Overall, the older patients were, the more likely they were to have been referred via a non-urgent referral.

The full breakdown of responses is shown in the charts below:

Figure 13: Route to diagnosis - by age group

The charts below compare the responses from this survey to the "NCIN routes to diagnosis 2015 update", for the four main leukaemia types.[2]

For the additional analysis, we have excluded from our data calculations those respondents who said their GP started treating them for another condition. In addition, the data for respondents reporting that their GP sent them to the hospital the same day has been combined with those seen as an emergency / A&E patient to reflect the NCIN category emergency presentation.

Like the NCIN report, Leukaemia CARE respondents were much more likely to be admitted via emergency presentation if they had ALL or AML, however in most cases a greater percentage of Leukaemia CARE respondents reported an emergency presentation when compared to the NCIN report.

A larger percentage of Leukaemia CARE respondents reported being diagnosed following a 'two-week referral' than the NCIN report and this was more frequent in CLL and CML patients.

Fewer Leukaemia CARE respondents said they were diagnosed following a GP non-urgent referral than the NCIN report, in particular those with CML.

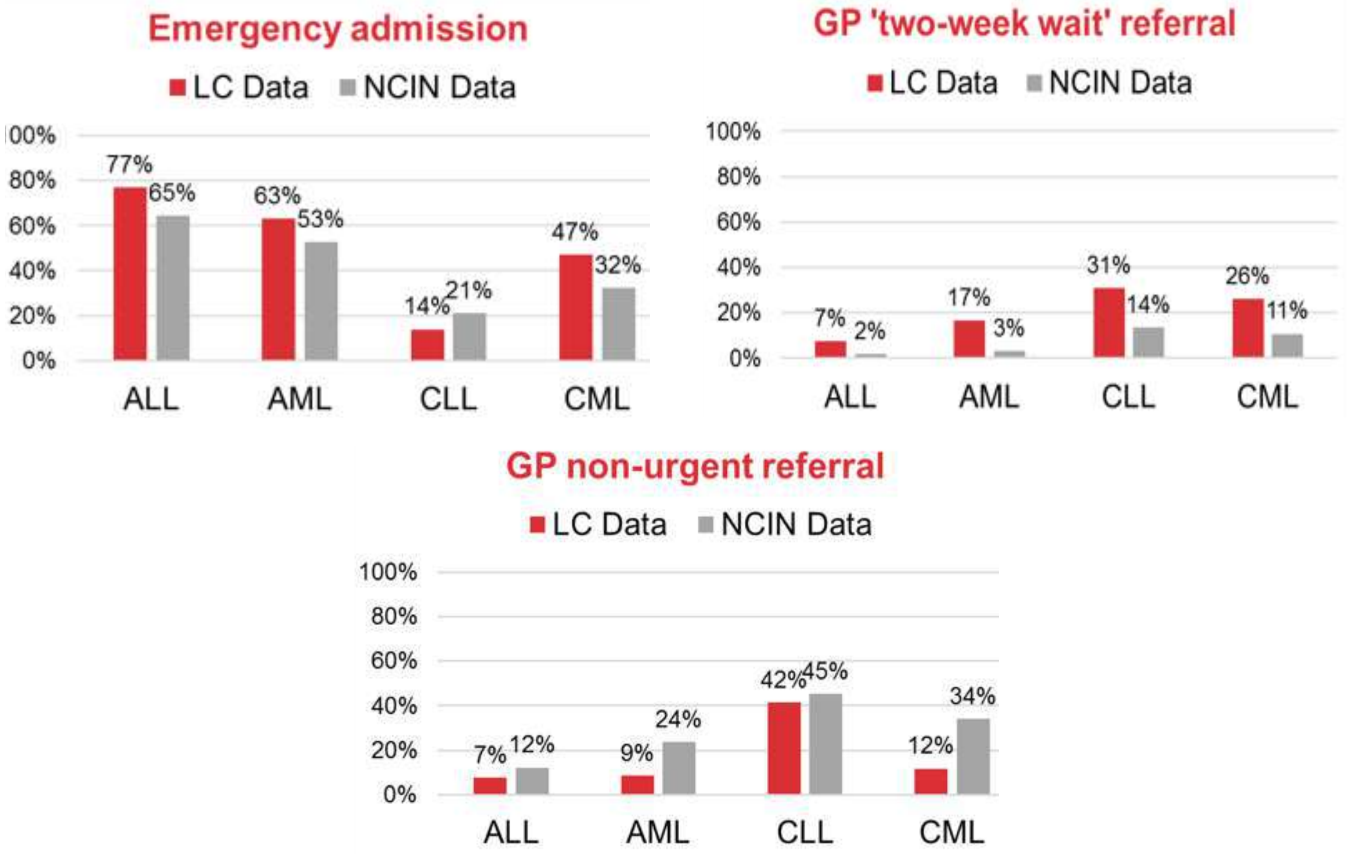


Figure 14: Route to diagnosis - by leukaemia type compared to NCIN

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[2] http://www.ncin.org.uk/publications/routes_to_diagnosis

3.2.4 Time from experiencing symptoms until seeing a GP

It is encouraging to see many patients not delaying seeing their GP when they start experiencing symptoms, 42% went within one month and 28% between 1-3 months. Although, 9% of respondents didn't see a GP until over a year from when they first started experiencing symptoms. The full breakdown can be seen in the chart below.

However, there are clear variations in the responses to this question between the different types of leukaemia. 63% of ALL respondents saw their GP within one month, compared to just 26% of CML respondents.

In addition, nearly all ALL patients had visited their GP within one year of first experiencing symptoms, compared to the other leukaemia types where higher percentages waited between 1-2 years or even over 2 years to make the first visit.

This indicates that symptoms are more severe/noticeable for some types of leukaemia and possibly result in earlier visits to GPs.

These results will support a targeted piece of work by Leukaemia CARE, raising awareness of leukaemia, and driving earlier diagnosis.

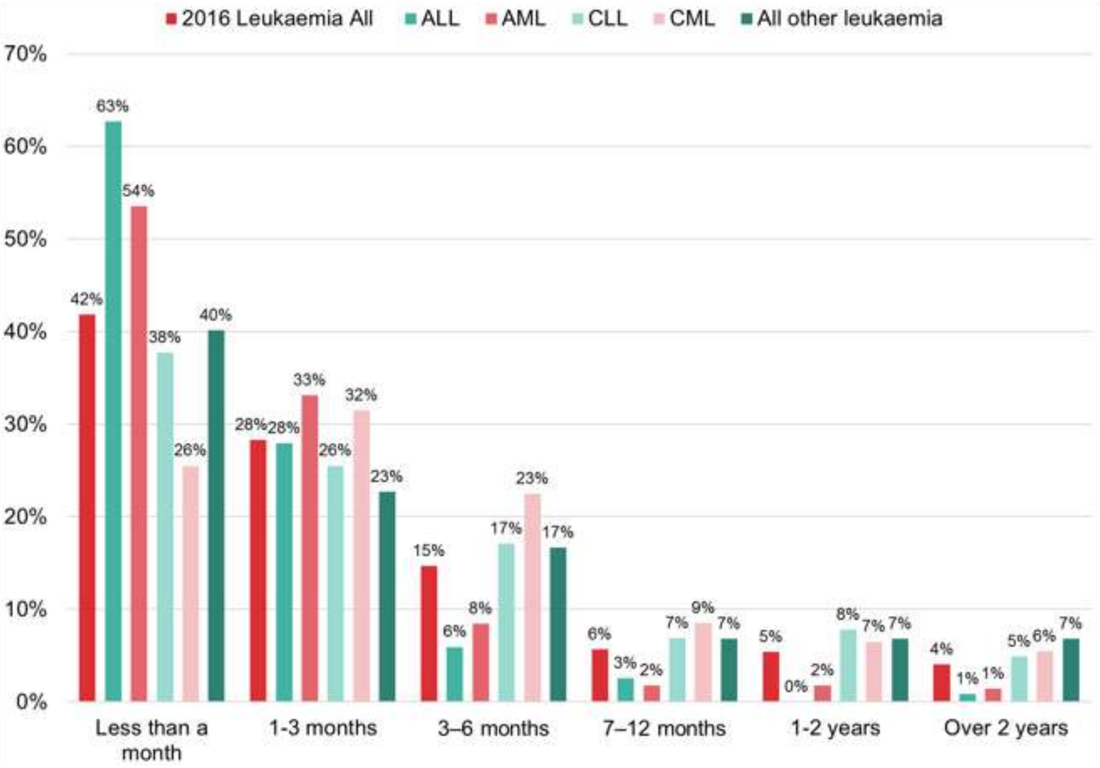

Figure 15: Time until saw GP - by leukaemia type

3.2.5 Number of GP visits before referral to hospital

1 in 5 respondents (22%) went to their GP more than twice before being referred to secondary care, this result is better than the 'all haematology' patients surveyed in the CPES 2015 survey, where it was 1 in 3 (33%). ALL and CML respondents were more likely to say they needed to see their GP more than twice before referral (29% ALL, 27% CML).

In addition, respondents who reported symptoms of muscle pain, headaches, frequent and repeated infections and pain in bone and joints, were more likely to say they saw their GP more than twice before being referred.

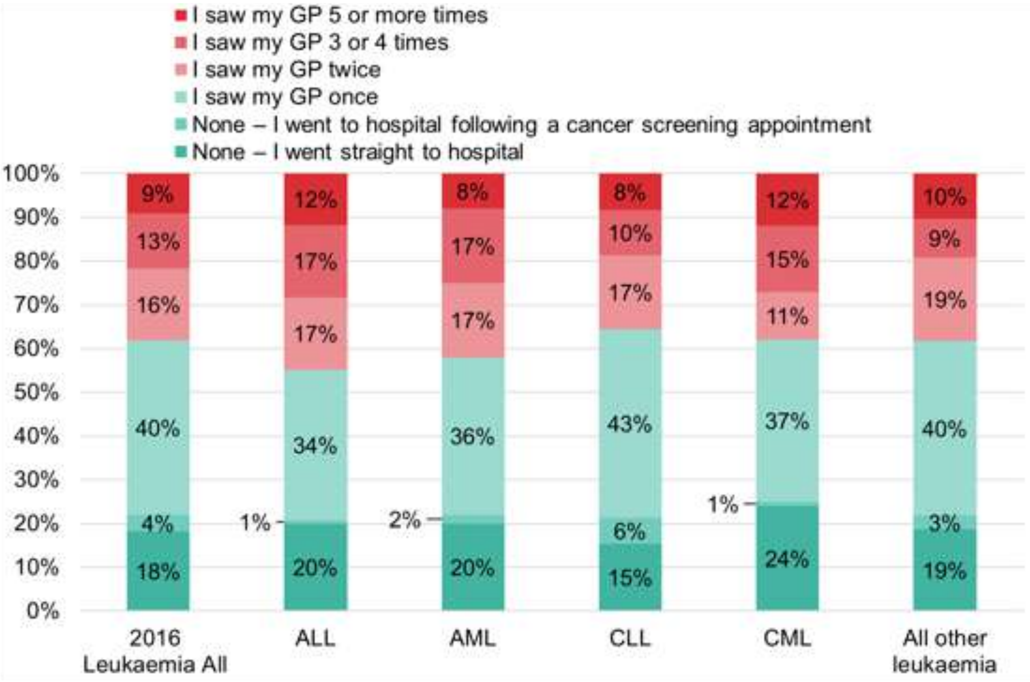

Figure 16: No. of visits to GP before referral – by leukaemia type

"GPs need a checklist available in front of them for the symptoms, as I went to them several times with many symptoms, however on blood testing it didn't show at that point. Yet I was very ill and felt I was being a pain, to the point I didn't go see them the last time I felt ill and ended up in the A&E with an issue that had been triggered by cancer." – [Other leukaemia patient, 45-54]

3.2.6 Respondents expectations of what was wrong

We asked respondents if they thought they might have cancer before they were diagnosed. Overwhelmingly 83% did not think it would be cancer at all, just 3% expected it to be cancer and 14% had some suspicions that they may have cancer.

"I suspected I might have leukaemia as a relative had already been treated for this and my symptoms were very similar." – [CLL patient, 65-74]

3.3 Finding out what was wrong

This section of the questionnaire asked respondents about their experiences during the course of their diagnosis. For example, it asked them questions about the information and explanations they were given, whether they were given a prognosis and who was with them when they were told they had cancer.

3.3.1 Respondents who were told about their particular type of blood cancer

95% of respondents said that when they were told their diagnosis they were told about leukaemia. Interestingly 2% of people were told they had a different type of blood cancer and 3% were told they had a different condition all together.

3.3.2 Respondents understanding that their diagnosis was a type of cancer

Over three-quarters of respondents (78%) knew their diagnosis was a type of cancer; 11% weren't sure that it was cancer but they thought it might be; 10% did not know that it was a type of cancer at all. There was not much variation between leukaemia types.

3.3.3 Respondents who had heard about their type of blood cancer

Following on from the previous question, respondents were then asked if they had heard of their overarching type of blood cancer i.e. leukaemia before they were diagnosed.

Whilst it is encouraging that 83% of respondents had heard of leukaemia, the majority (68%) didn't actually know anything about it. This strongly indicates that there is still work to be done to help educate the public on leukaemia, what it is, how it affects the body, and the symptoms to be aware of.

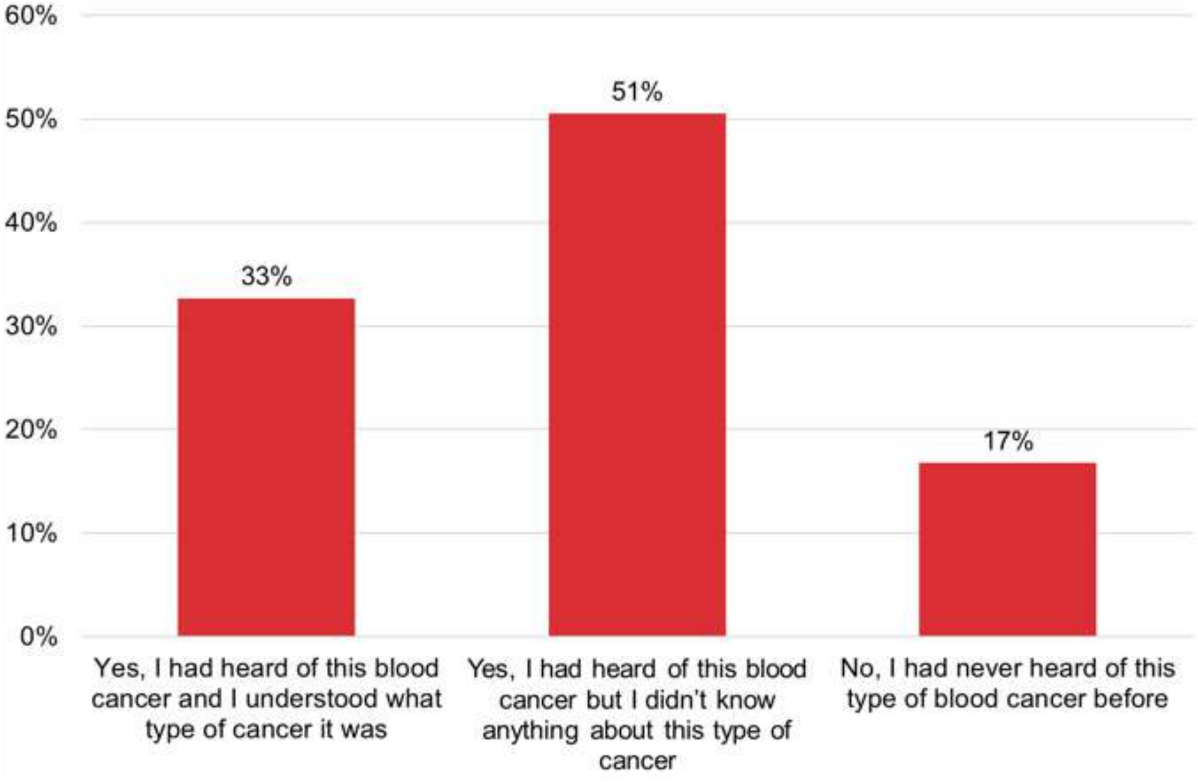

Figure 17: Respondents who had heard of leaukemia

3.3.4 Understanding the explanation of what was wrong

When asked if they understood the explanation of what was wrong with them, half of respondents (50%) said they completely understood the explanation; 44% said they understood some of it and 6% did not understand the explanation of what was wrong with them.

Respondents from Arm 2 were less likely to say that they completely understood the explanation of what was wrong with them (38%, compared to 56% Arm 1) and more likely to say they did not understand the explanation (11%, compared 4% Arm 1). This supports the theory that patients with a lack of understanding of their diagnosis are more likely to reach out to charities for additional information and support.

There is also variation between leukaemia types; a larger proportion of AML patients reported a complete understanding (56%), and a smaller proportion of CML patients (47%). In addition, 8% of ALL respondents said they didn't understand the explanation at all.

This compares less favourably than the 'all haematology' patients surveyed in the CPES 2015 survey, where 59% said they completely understood the explanation of what was wrong with them. In turn both these results are lower than the overall percentage of 'all cancer' patients, which was 73%.

These results show that many leukaemia patients are leaving their diagnosis meeting without a full understanding of what is wrong with them, and that more information needs to be given at this point in their cancer journey.

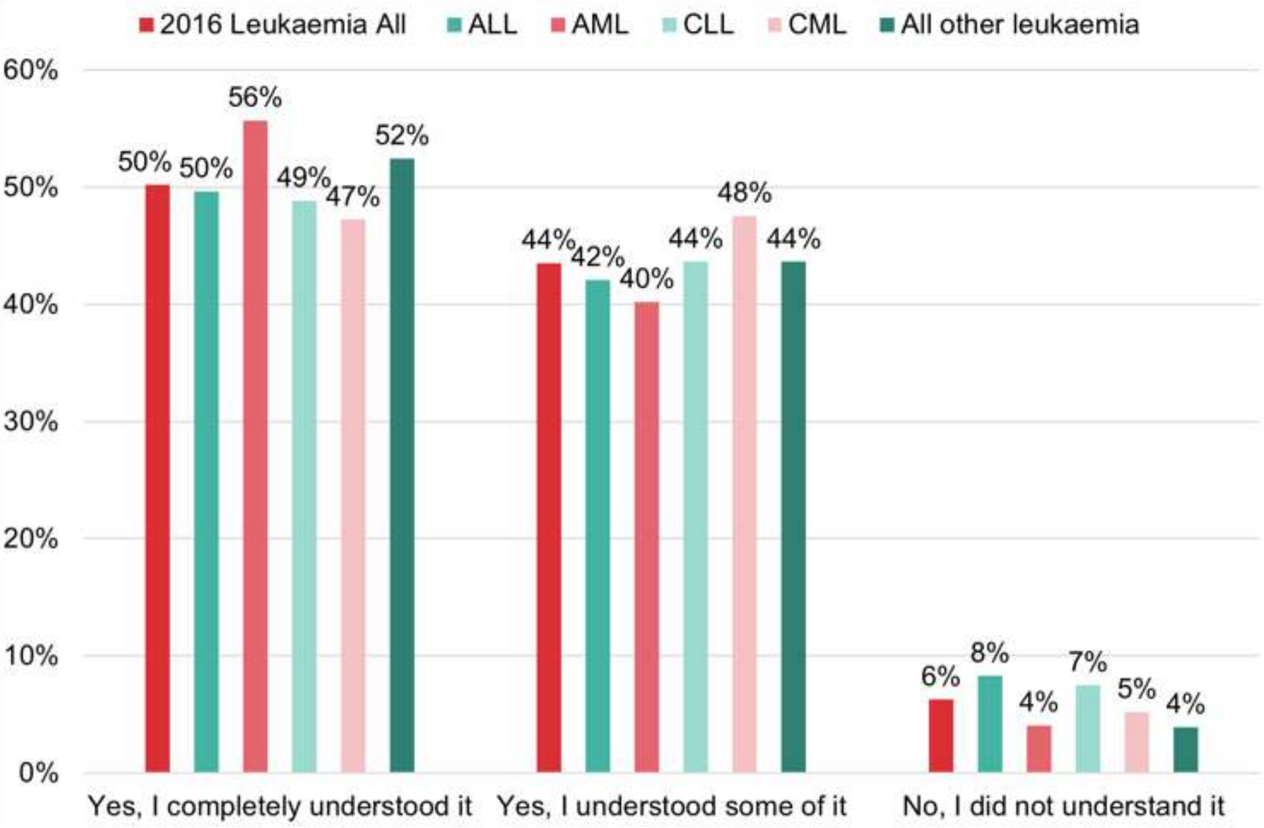

Figure 18: Respondents understanding of the explanation of diagnosis – by leukaemia type

"The way the diagnosis is delivered can be poor and should include an information and contact pack for newly diagnosed patients and their carers." – [CLL patient, 55-64]

"The consultant should have had a nurse or someone to take me aside and explain everything instead of leaving me in shock." – [CLL patient, 75-84]

3.3.5 Information given on prognosis / survival chances

We asked respondents what they were told about their prognosis or likely survival chances for their cancer, a fifth of people (20%) said they were not told anything.

Out of the four main types of leukaemia, CLL patients were more likely not to be told about their prognosis (24%), compared to CML patients where just 14% were not told anything and 8% of 'Other leukaemia' patients. Interestingly, despite being likely to have the least positive prognosis, many AML patients were still told about their survival chances, with only 17% not being told anything.

3.3.6 Accompanying person at diagnosis

We asked respondents who was with them when they were told they had cancer. As might be expected, nearly half of the respondents (46%) were with their spouse or partner; however, it is a concern that 40% were on their own.

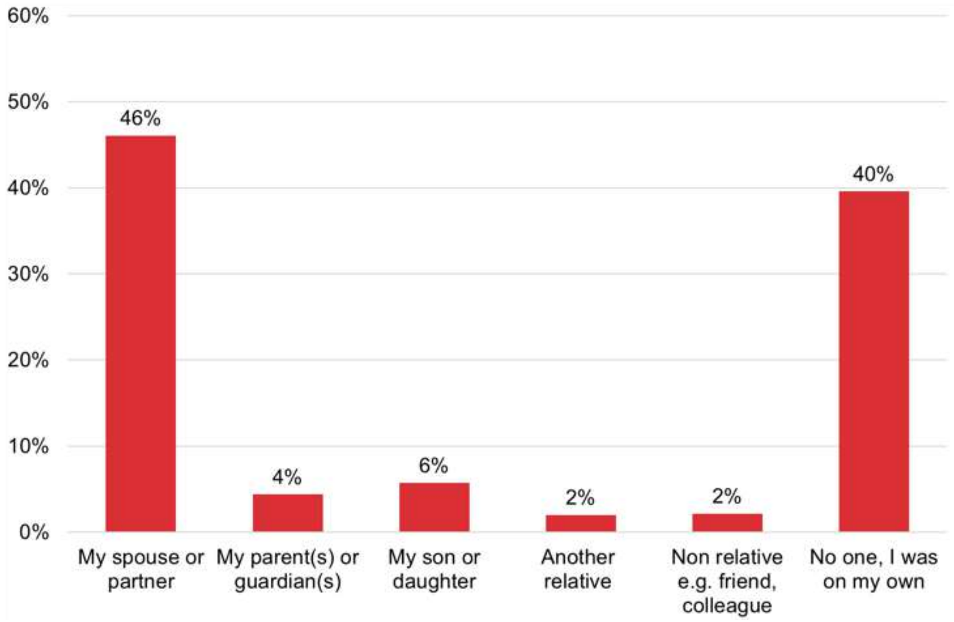

Figure 19: Accompanying person at diagnosis

Female respondents were less likely to report taking a spouse or partner and more likely to have support from another source at their diagnosis.

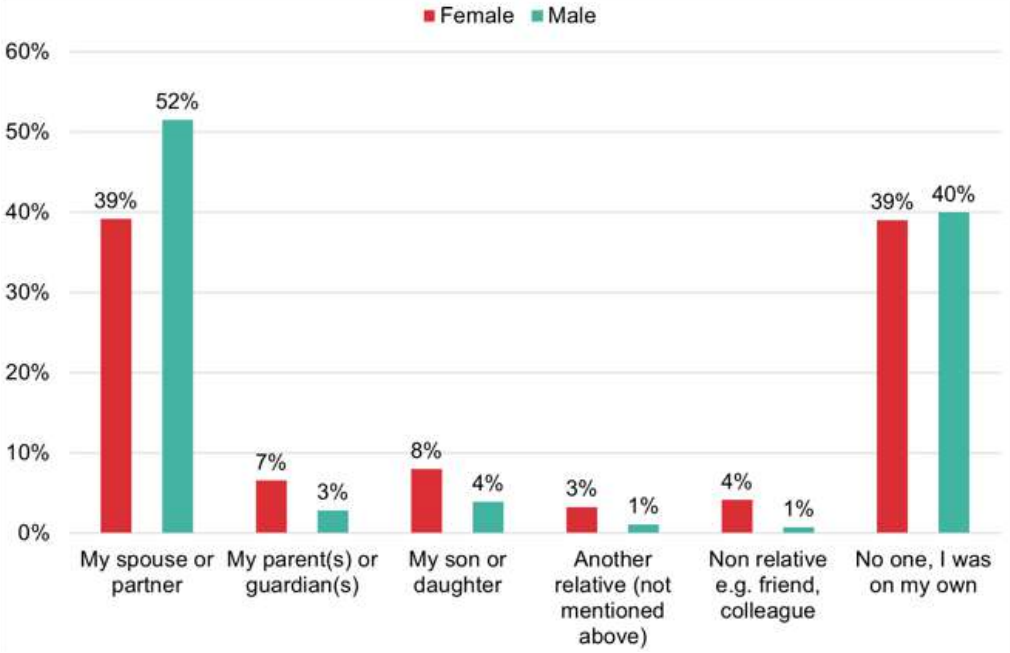

Figure 20: Accompanying person at diagnosis - by gender

The charts below show the variation between age groups, some of the key differences are:

- Significantly fewer 16-24 year olds were unaccompanied than the other age groups
- As might be expected, younger respondents were less likely to take a spouse/partner and more likely to take a parent/guardian
- 25-34 year olds were more likely to take a friend or colleague
- Over 85's were less likely to have a spouse or partner accompany them and more likely to be with their children

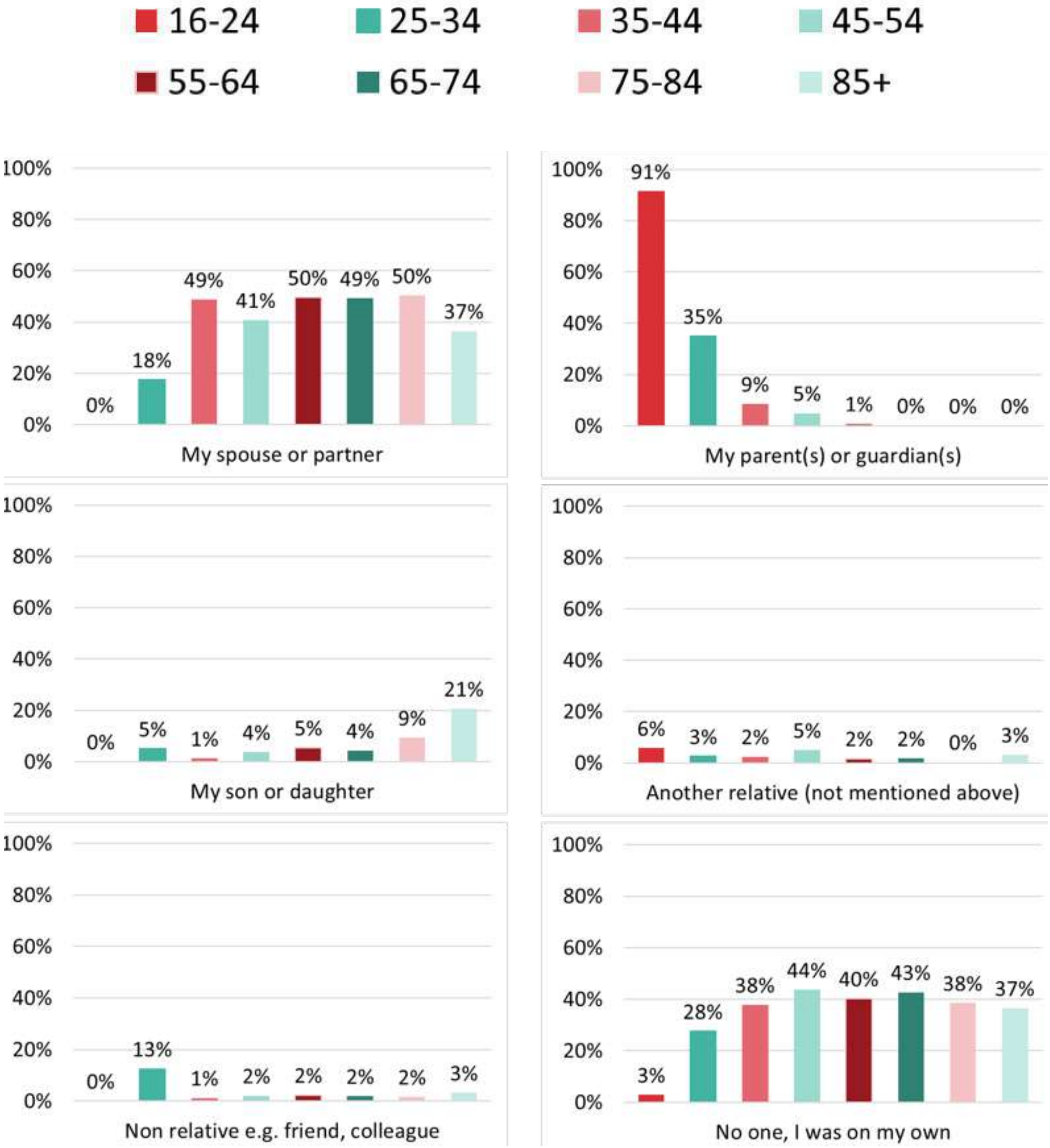

Figure 21: Accompanying person at diagnosis - by age group

There are some distinct differences in the proportion of unaccompanied respondents by leukaemia type. Acute leukaemia patients are more likely to take somebody with them; this may be due to the rapid nature of diagnosis.

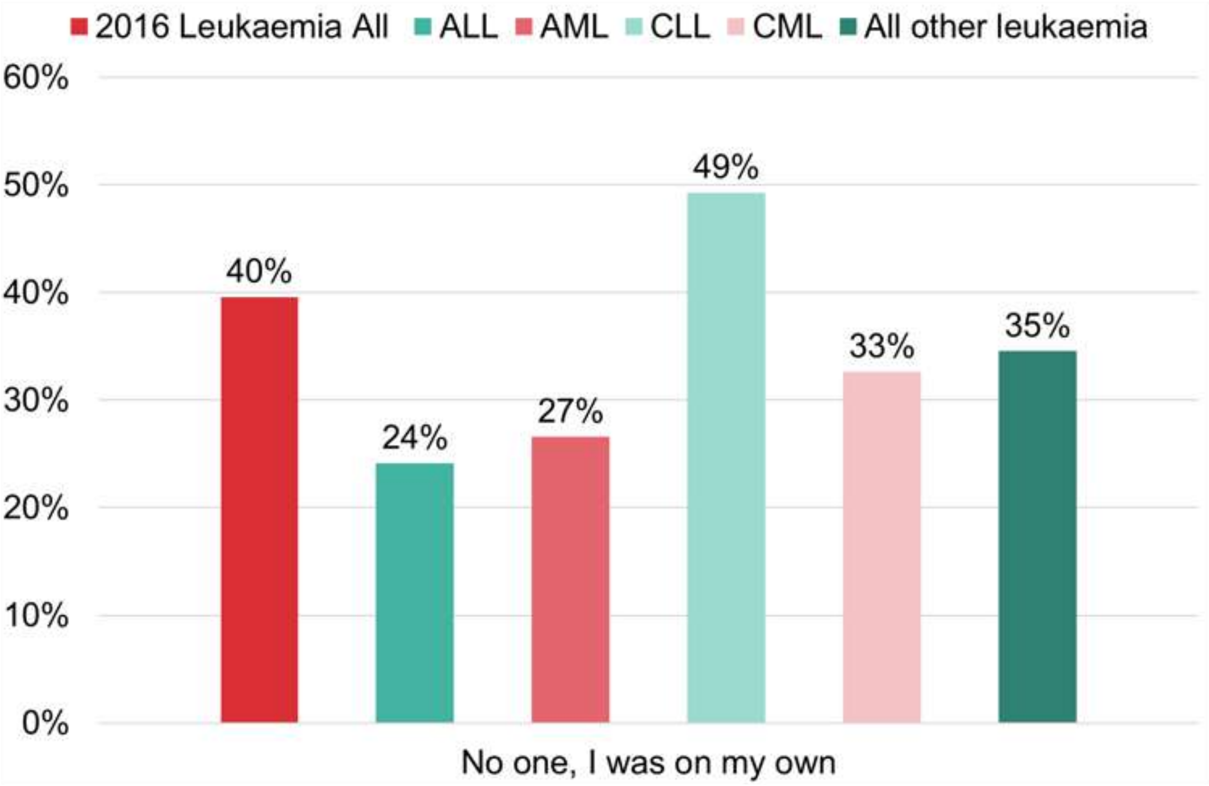

Figure 22: Respondents unaccompanied to their diagnosis meeting - by leukaemia type

"I would have liked to have been asked by staff if I would have liked to have a friend or relative with me prior to informing me of my diagnosis (I was taken into a room on a few occasions, told my diagnosis, but never asked if I would like someone with me)." – [CML patient, 35-44]

Accompanied at diagnosis – impact on understanding of diagnosis

Whilst the main benefit of being accompanied at diagnosis is associated with emotional support, we were interested to see if there was any impact on the understanding of the diagnosis. Whether having another person present to ask questions, take notes whilst the shock of diagnosis sinks in for the patient and discuss once the meeting has finished is a benefit in this aspect.

The chart below illustrates that those accompanied are more likely to have a complete understanding of their diagnosis, whilst those unaccompanied are nearly twice as likely to not understand it.

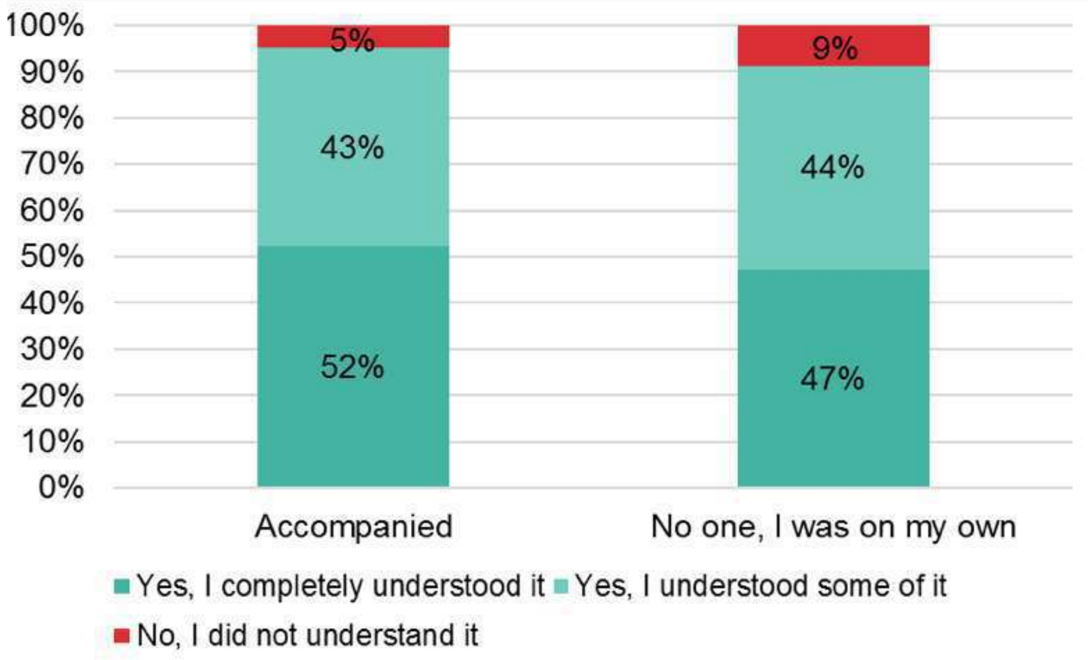

Figure 23: Respondents understanding of diagnosis - by accompanied to diagnosis meeting

3.4 Treatment and care

In this section of the questionnaire we asked respondents about their treatment and care, including questions on: 'watch and wait'; involvement in decisions about treatment and care; impact of treatment, including side effects and participation in clinical trials.

3.4.1 Treatment vs ‘watch and wait’

Some patients who have leukaemia do not start treatment straight away. If patients are not being treated they have regular check-ups and this is known as ‘watch and wait’ or ‘active monitoring’. This is mainly relevant for patients with CLL. Almost all patients with CML or with acute leukaemia will start treatment soon after diagnosis. Although patients on ‘watch and wait’ do not have to deal with side effects of treatment, it can be an incredibly anxious time. We asked respondents if they were told they would start treatment immediately, or be put on a ‘watch and wait’ regime. The chart below illustrates the responses given:

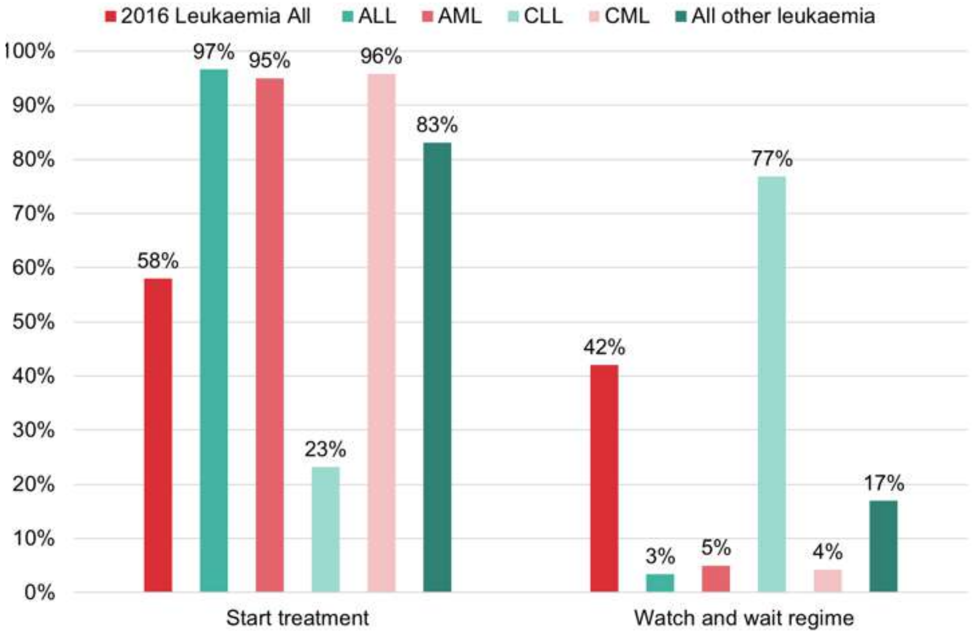

Figure 24: Treatment vs ‘watch and wait’- by leukaemia type

3.4.2 Respondents understanding of reasons for 'watch and wait'

Of those respondents who were placed on 'watch and wait', over half (59%) fully understood the reasons, a third (33%) mostly understood the reasons and just 8% did not understand the reasons.

There is a pronounced difference between the two patient cohorts on this question, more respondents from Arm 2 (anonymous online cohort) reported not fully understanding the reasons they were put on 'watch and wait'. This may suggest that where patients are not being given enough information and explanation about 'watch and wait', they are reaching out for support from organisations such as Leukaemia CARE.

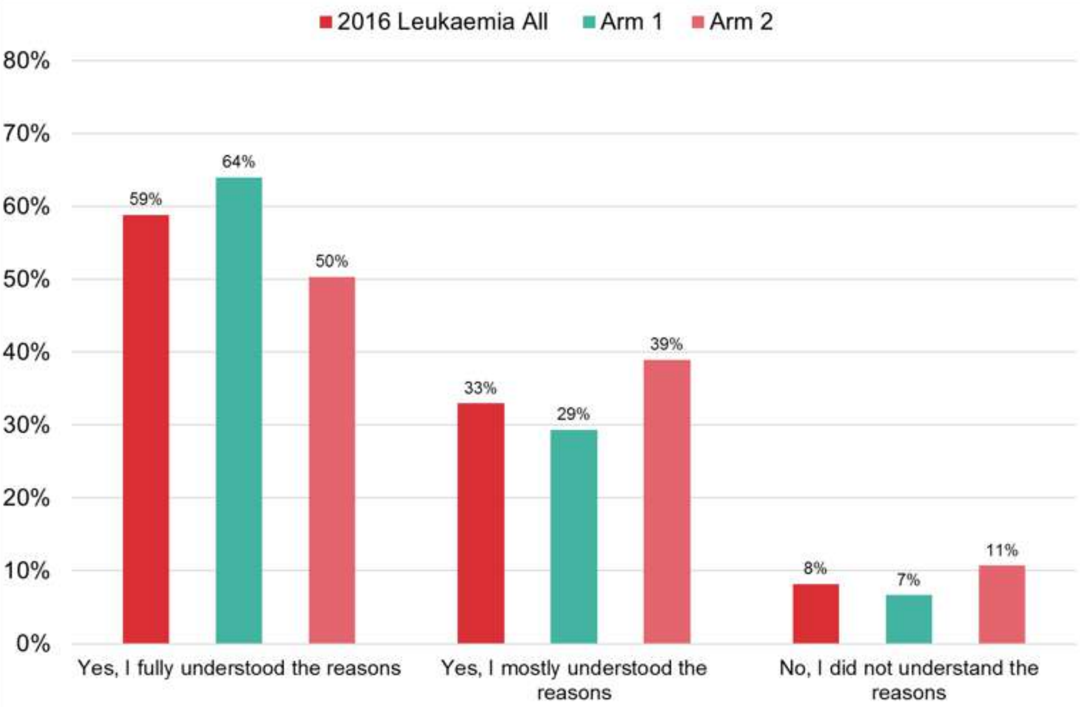

Figure 25: Understanding of reasons for 'watch and wait' - by patient cohort

3.4.3 Concerns around 'watch and wait'

46% of respondents did not have any concerns or worries about being placed on 'watch and wait'. However, the majority (54%) had at least some worries, 12% said they were very concerned/worried.

Again, there is a big difference between the two patient cohorts, over a quarter (26%) of the Arm 2 respondents were very concerned/ worried about being on 'watch and wait' compared to just 4% of the Arm 1 respondents.

These results indicate that the level of understanding for being referred to 'watch and wait' is related to the concerns and worries a patient then experiences i.e. where there is less understanding there is more worry, and vice versa. However, even where there is a reasonable level of understanding, there can still be an element of worry or concern. Leukaemia CARE offers a number of resources that can be accessed by patients to help alleviate some of the worries and concerns, and provide reassurance; including a 24/7 CARE line providing emotional and practical support as well as medical advice.

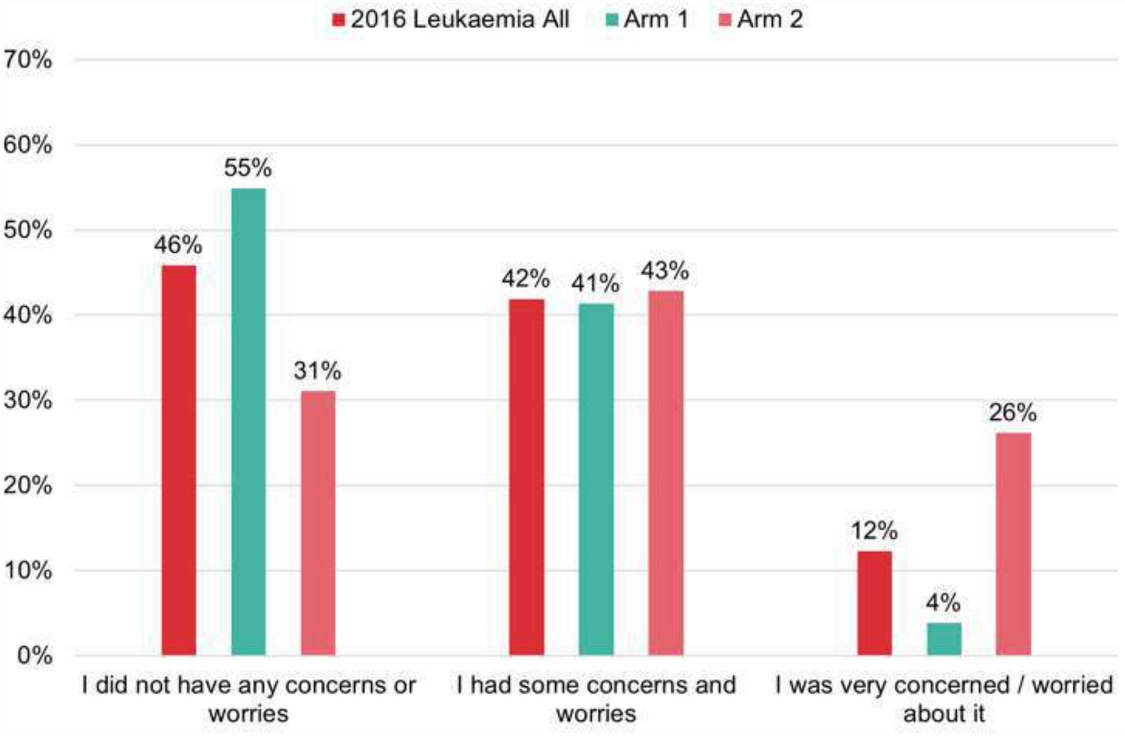

Figure 26: Concerns around ‘watch and wait’ - by patient cohort

3.4.4 Written information on ‘watch and wait’

Of those who felt they needed written information on ‘watch and wait’, 56% of respondents were given it, and felt it was easy to understand. A third of respondents (33%) were not given any written information about their ‘watch and wait’ regime.

The chart below illustrates the relationship between the level/quality of written information given to patients about ‘watch and wait’, and how worried they then felt about being placed on this form of active monitoring.

Respondents receiving written information were much more likely not to have any concerns or worries. The results also indicate that patients being given information that they find difficult to understand has a more negative effect than being given no information at all.

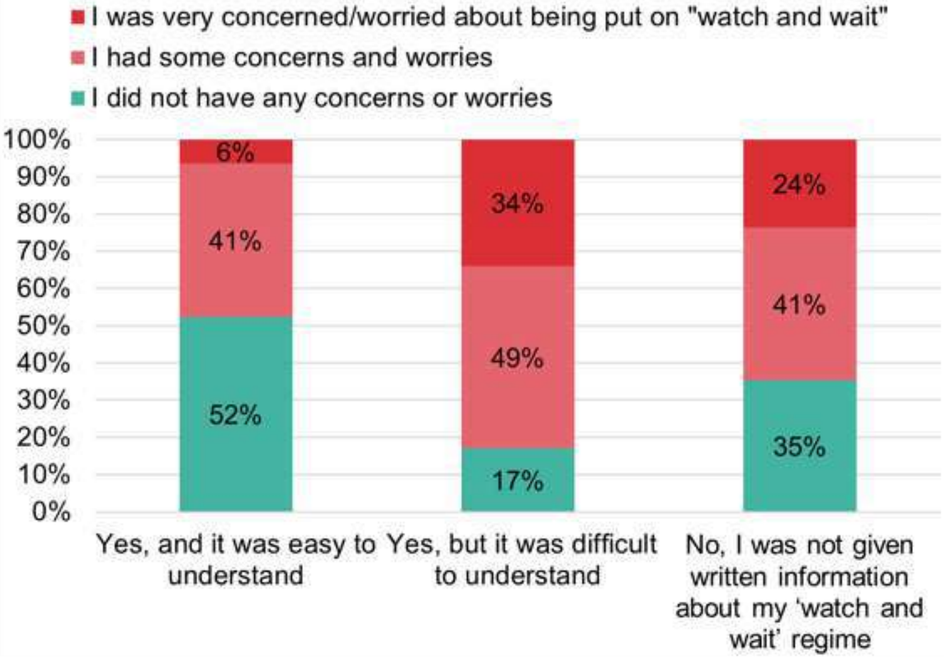

Figure 27: Concerns around ‘watch and wait’ - by quality/ quantity of written information given

Leukaemia CARE understands that the provision of information is extremely important to patients, so they fully understand what is happening to them and why, as this often has a big impact on their emotional well-being. To this end we have developed a downloadable 'Step by Step' guide to 'watch and wait'; outlining what 'watch and wait' is, when and why it is used, questions patients may want to ask their medical team, how patients can find support and a section for carers.

http://www.leukaemiacare.org.uk/resources/watch-and-wait

3.4.5 Change from 'watch and wait' to treatment

When asked why respondents may have moved from 'watch and wait' to treatment, the main reasons given were because their disease had progressed (53%) or because their symptoms had gotten worse (23%).

3.4.6 Decisions about treatment and care

We asked respondents if they felt they were involved as much as they wanted to be in decisions about their treatment and care. The majority (72%) said that they were definitely involved as much as they wanted, 21% were involved to some extent and 6% replied that no, they were not involved as much as they wanted to be.

"I appreciated being included at all stages of my treatment, with making decisions in an inclusive manner." - [ALL patient, 55-64]

There were some clear differences in experiences between the two groups of patients. 79% of Arm 1 felt they were definitely involved in decisions, compared to 59% of Arm 2, as shown on the graph below.

Between leukaemia types, ALL and CML patients were least likely to say they had definitely been involved as much as they wanted to be (67%), and CML had the largest percentage of respondents who felt they hadn't been involved as much as they wanted to be (9%).

Research has shown that better communication between doctors and patients is strongly associated with a better patient experience[3] and this is also supported by NICE guidance[4].

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[3] http://qualitysafety.bmj.com/content/23/7/534

[4] https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making

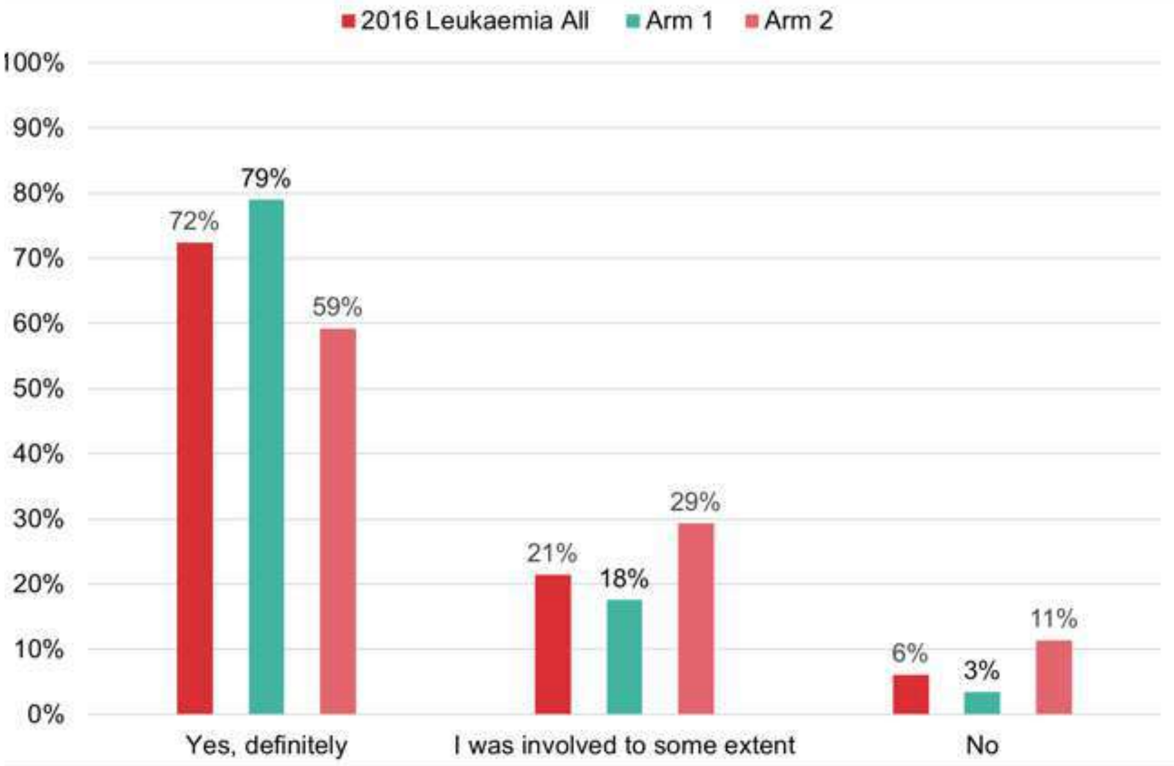

Figure 28: Involvement in decision about treatment and care - by patient cohort

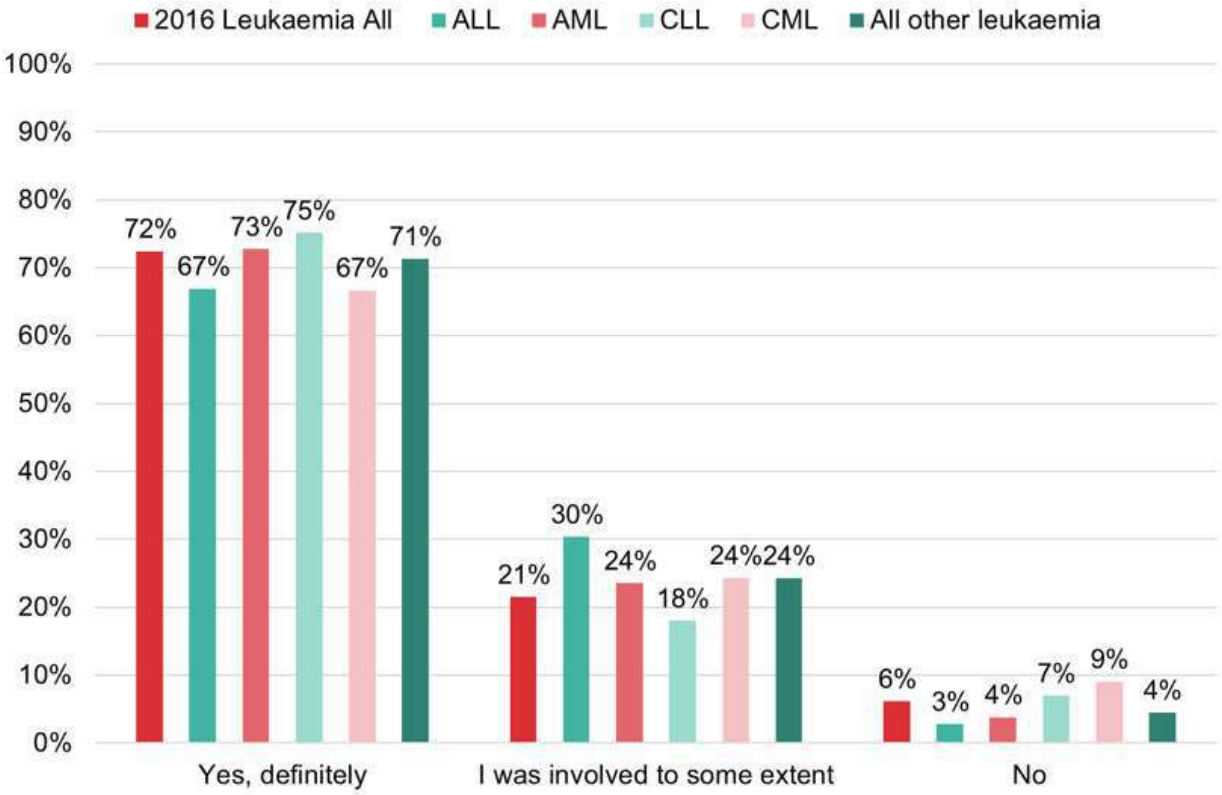

Figure 29: Involvement in decision about treatment and care - by leukaemia type

Involvement in decisions about treatment and care - CLL breakdown

We were interested to see how involved CLL patients still on 'watch and wait' felt in decisions about their care and treatment, compared to those who had gone on to start treatment As the chart below illustrates, CLL patients still on 'watch and wait' reported feeling less involved, only 50% said they definitely felt involved as much as they wanted to be, compared to 81% who had started treatment. In addition 22% on 'watch and wait' said they were not involved as much as they wanted to be, compared to just 3% who had started treatment.

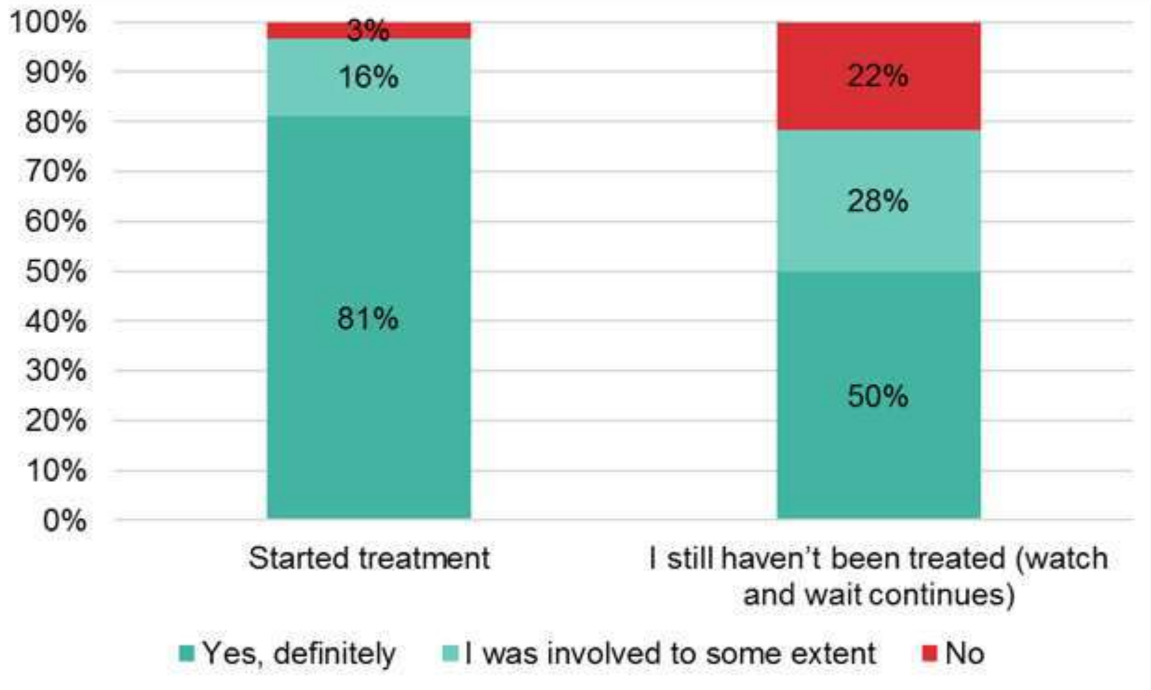

Figure 30: Involvement in decision about treatment and care - by CLL treatment journey

3.4.7 Length of time from diagnosis to start of treatment

We asked respondents how long it was from their diagnosis to when they started treatment. Patients with CLL are much more likely to be put on ‘watch and wait’ and therefore not start treatment until much later than the other leukaemia types; a quarter of the CLL respondents reported waiting longer than 2 years and a further 22% said they still haven’t started treatment.
The other leukaemia groups reported a much shorter wait from diagnosis to treatment, with the majority starting treatment the same day, or within a week of diagnosis.

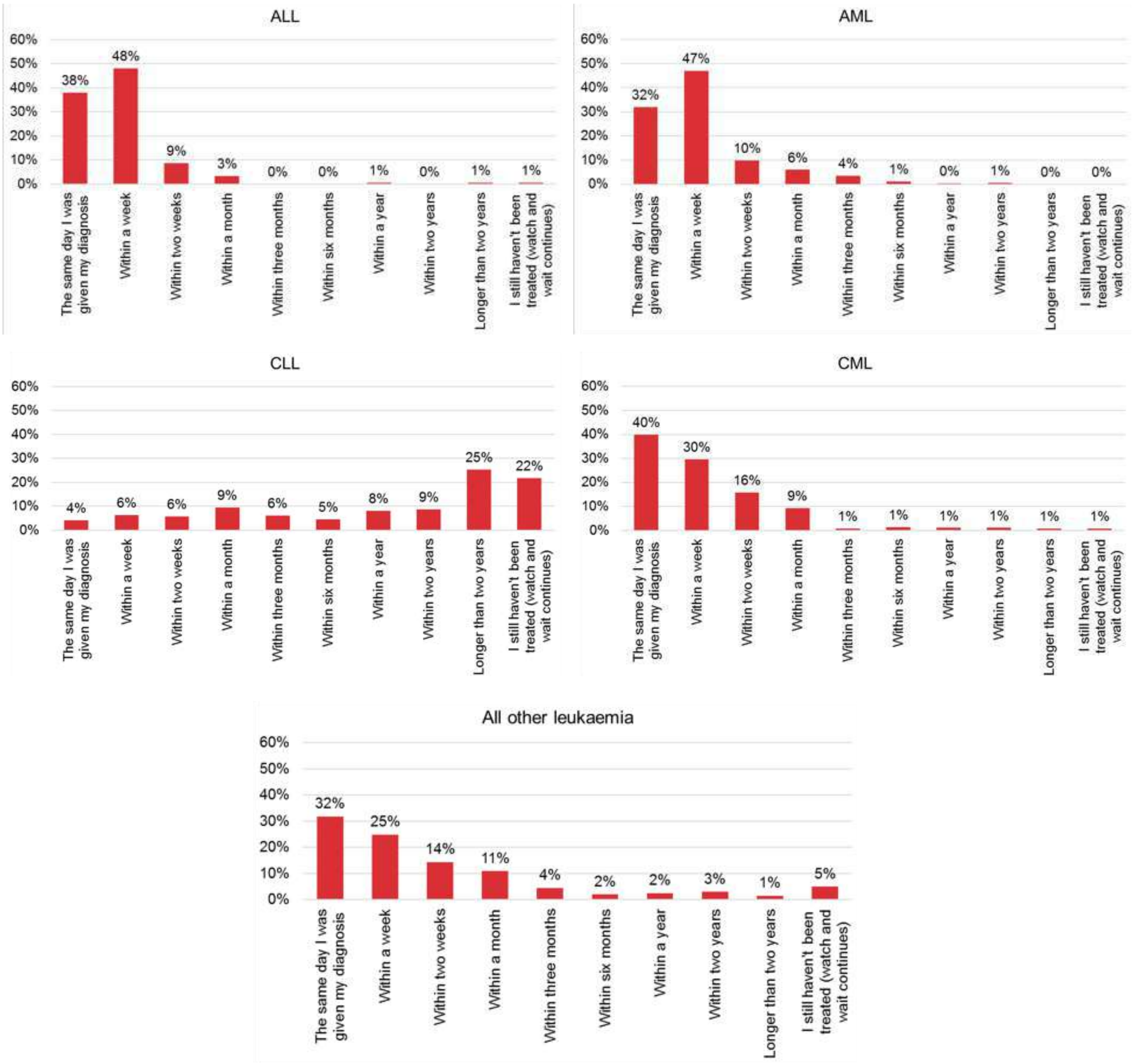

Figure 31: Time from diagnosis to start of treatment - by leukaemia type

Length of time to start of treatment - CLL breakdown

In addition, we looked at the responses from CLL patients who said that they had been put on ‘watch and wait’. A third of patients said that they did not start treatment until more than two years after their diagnosis and 29% said that they were still on ‘watch and wait’.

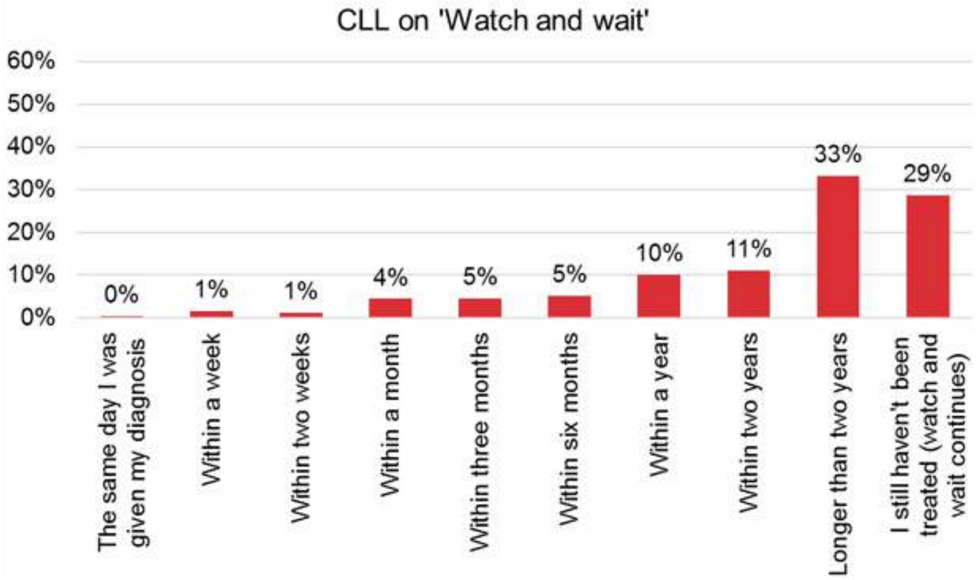

Figure 32: Time from diagnosis to start of treatment - by CLL respondents who were on ‘watch and wait’

3.4.8 Treatment options

Respondents were asked if they were offered a choice of treatment options, under a third (31%) said they were given a choice whilst the majority (69%) said that they were not.

To a certain extent it is surprising that there is so little variation between different leukaemia types in the number of patients reporting that they were offered a choice of treatment options.

For example, in CML, there are a number of NICE approved first line treatments available.

This raises potential questions around whether patients are not being presented with a choice of different options or, alternatively, whether clinicians are informing patients of several options but recommending a particular option, leading patients to therefore not consider the other avenues available as potential choices for them.

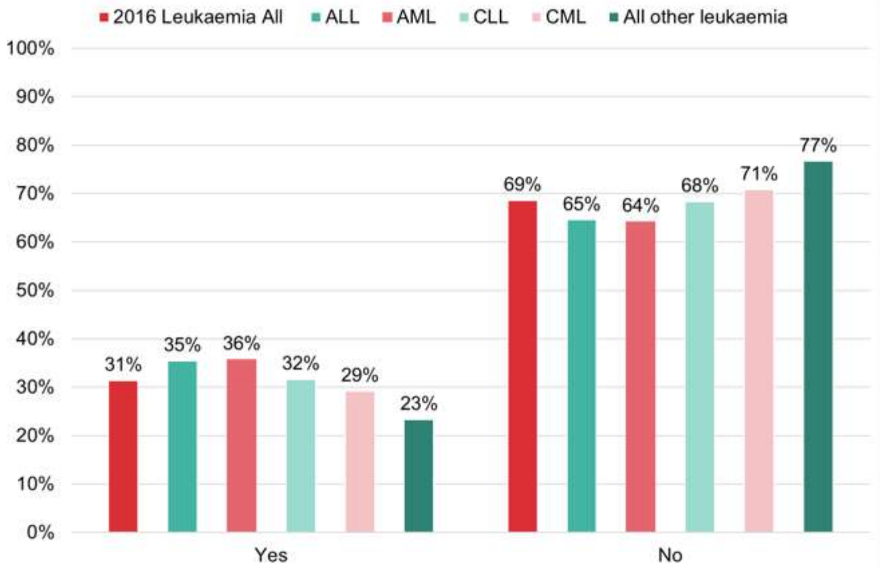

Figure 33: Offered a choice of treatment options - by leukaemia type

3.4.9 Impact of treatment on symptoms

Encouragingly, overall 76% of respondents reported a significant or complete improvement of their symptoms following their most recent/current treatment – this is particularly relevant, as for some patients a key aim of their treatment will be symptom relief.

CML respondents were less likely to say that there had been an improvement with their symptoms following treatment.

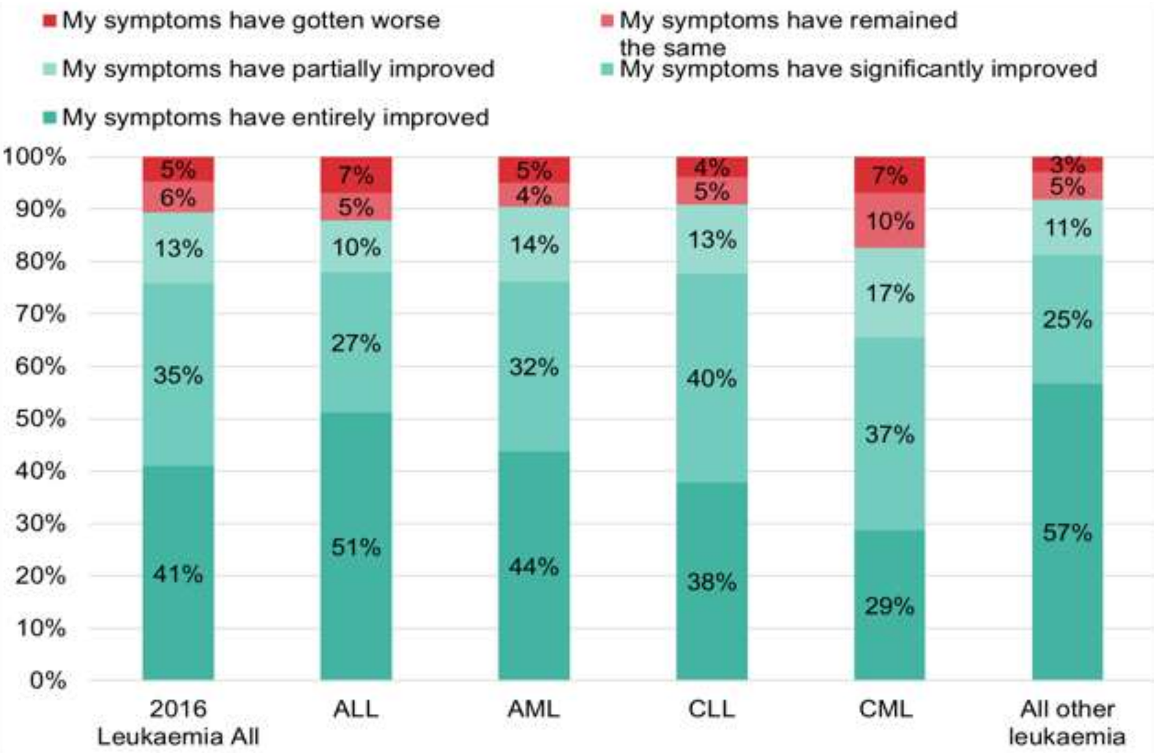

Figure 34: Impact of treatment on symptoms - by leukaemia type

3.4.10 Side effects during recent/current treatments

Treatment for many cancers can cause patients to experience side effects. We asked respondents to tell us which side effects they had encountered following their most recent or current treatment. Fatigue was most prevalent, with 60% of people saying they had experienced this; 30% had experienced muscle or joint pain and 26% nausea or vomiting. Just 8% did not have any side effects.

The following side effects were particularly prevalent for some types of leukaemia:
Neutropenia - experienced by 44% of ALL and AML

Muscle or joint pain - experienced by 53% of CML

Bone and joint pain - experienced by 47% of CML

Nausea or vomiting - experienced by 44% of ALL and 39% of AML

Sore mouth - experienced by 40% of ALL and AML

Hair loss - experienced by 54% of AML

Leukaemia CARE understands that patients may have questions about the side effects of treatment, and offers information about side effects and advice on how they can be managed. One of the resources is a downloadable booklet covering some of the most common side effects http://www.leukaemiacare.org.uk/resources/step-by-step-on-common-side-effects-of-treatment

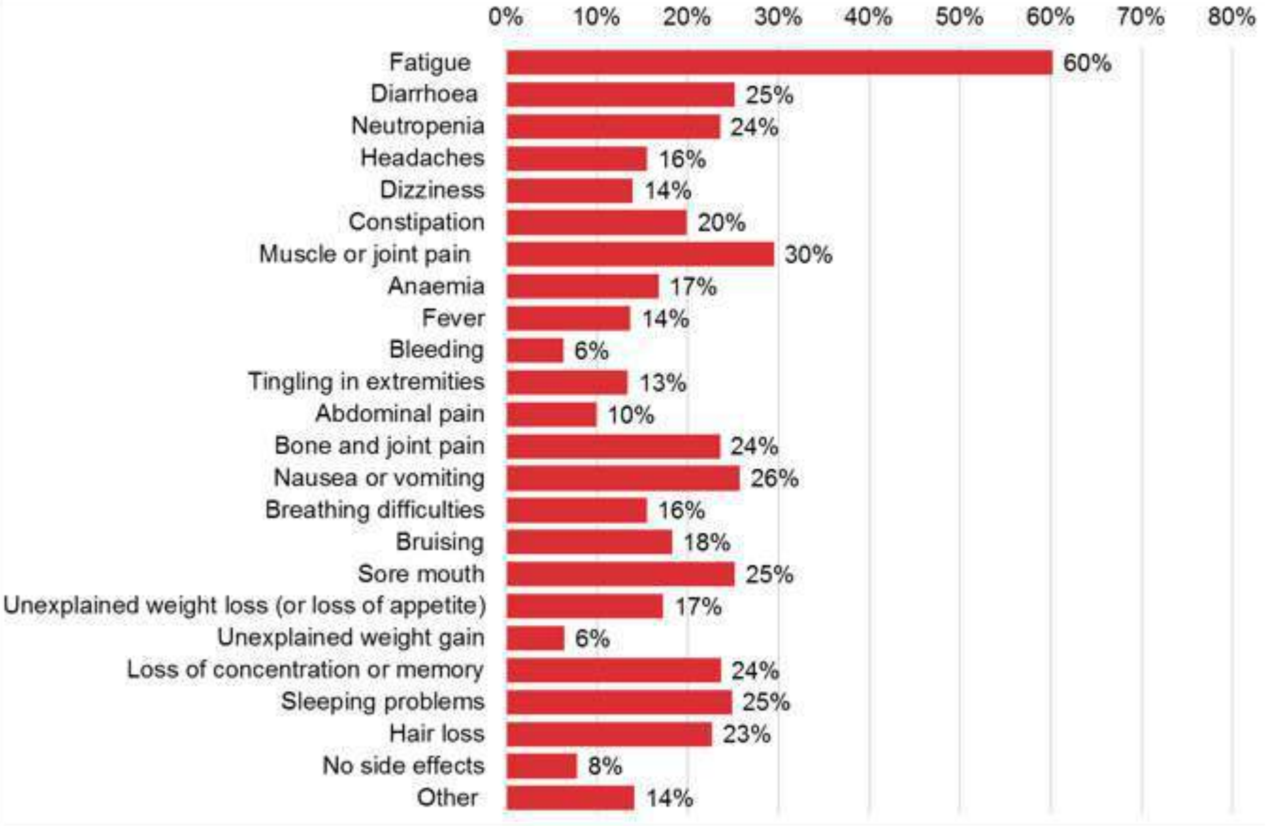

Figure 35: Side effects encountered during most recent/current treatment

We then asked respondents if they were hospitalised as a result of their side effects, over a third (34%) said they were, with 66% saying they were not. However, as the chart below shows, there are some big differences between the different leukaemia types. Over half of respondents with ALL and AML were hospitalised compared to much smaller percentages of those with either CLL or CML.

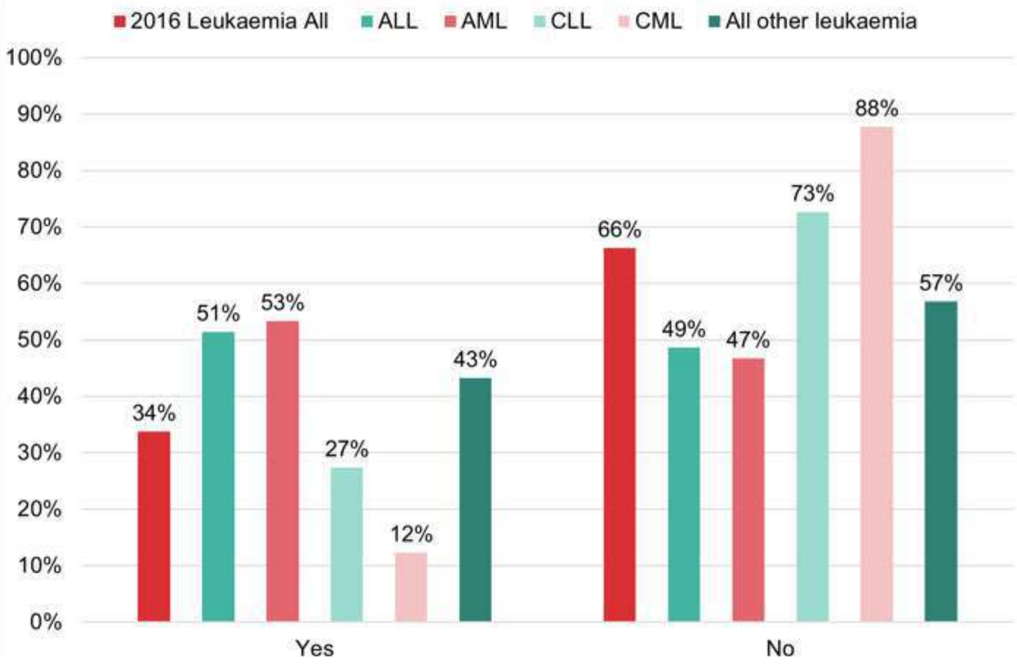

Figure 36: Hospitalised as a result of side effects - by leukaemia type

This ties in with the overall impact of side effects patients experienced, with a greater percentage of ALL and AML patients reporting the side effects of their most recent treatment having a large impact or being intolerable, as the chart below shows.

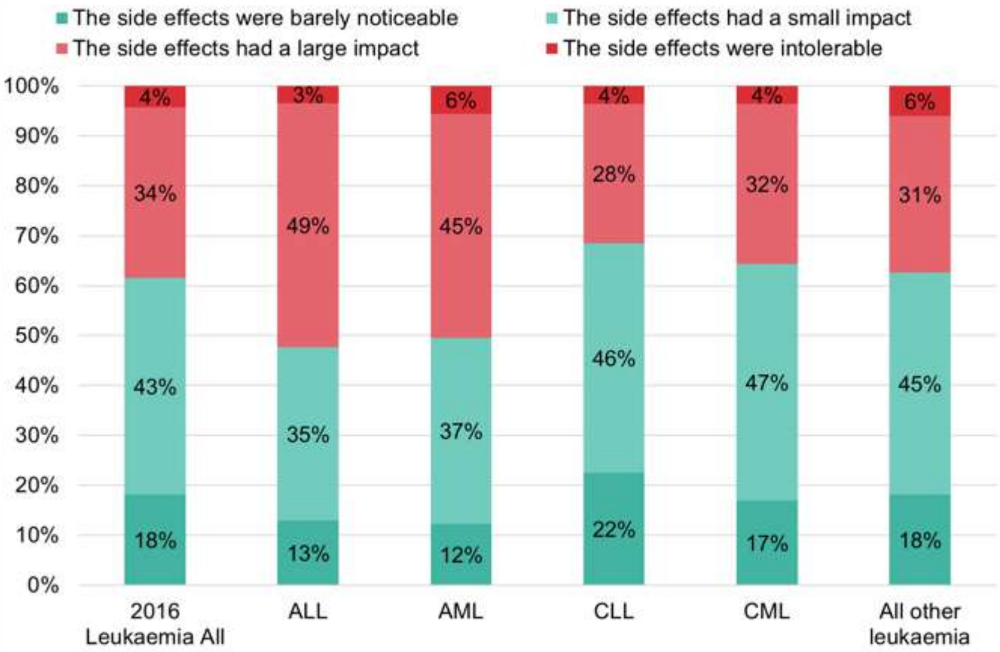

Figure 37: Impact of side effects - by leukaemia type

"The side effects are worse than the actual illness. If a medication came out that was not as effective but side effects were at a minimum, I would probably opt for that. I work in a mental and physical job and have a family. It's very hard." – [CML patient, 35-44]

3.4.11 Clinical trials

Overall, half of respondents (51%) had been given the option to participate in a clinical trial but patients with acute leukaemia were more likely to have been given this option, as the chart below shows:

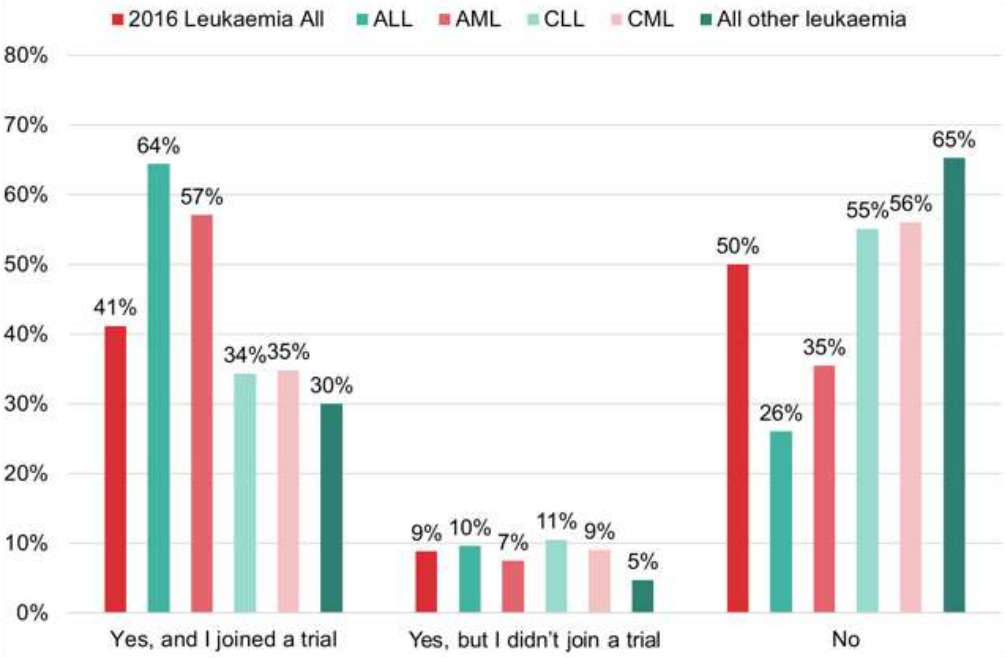

Figure 38: Given option to participate in clinical trial - by leukaemia type

Overall, of those who were offered the opportunity to join a trial, 82% went on to participate. This demonstrates that leukaemia patients have a high inclination to engage with the clinical trial process and that clinicians need to be encouraged to discuss the subject of clinical trials with their patients. When asked why they joined a trial 55% of respondents said one of the reasons was because their consultant recommended it.

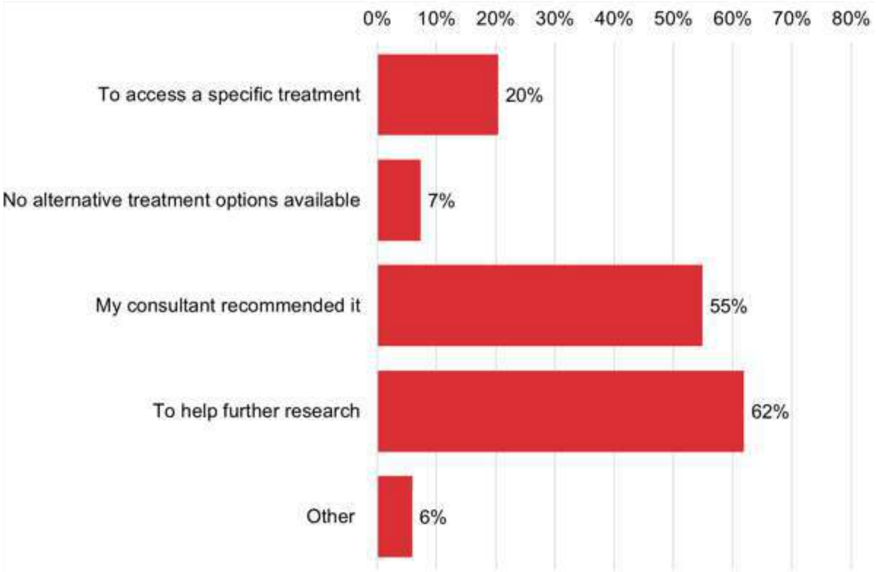

Figure 39: Reasons for participating in a clinical trial

For those who chose not to join a trial, despite having being offered the opportunity, a range of reasons were offered. The main reason given by respondents for not participating was not being eligible/ rejected for the trial (28%). Of those who were eligible but decided not to participate the most frequently reported reasons were due to concerns about safety (16%) and location of the trial being too far to travel (15%).

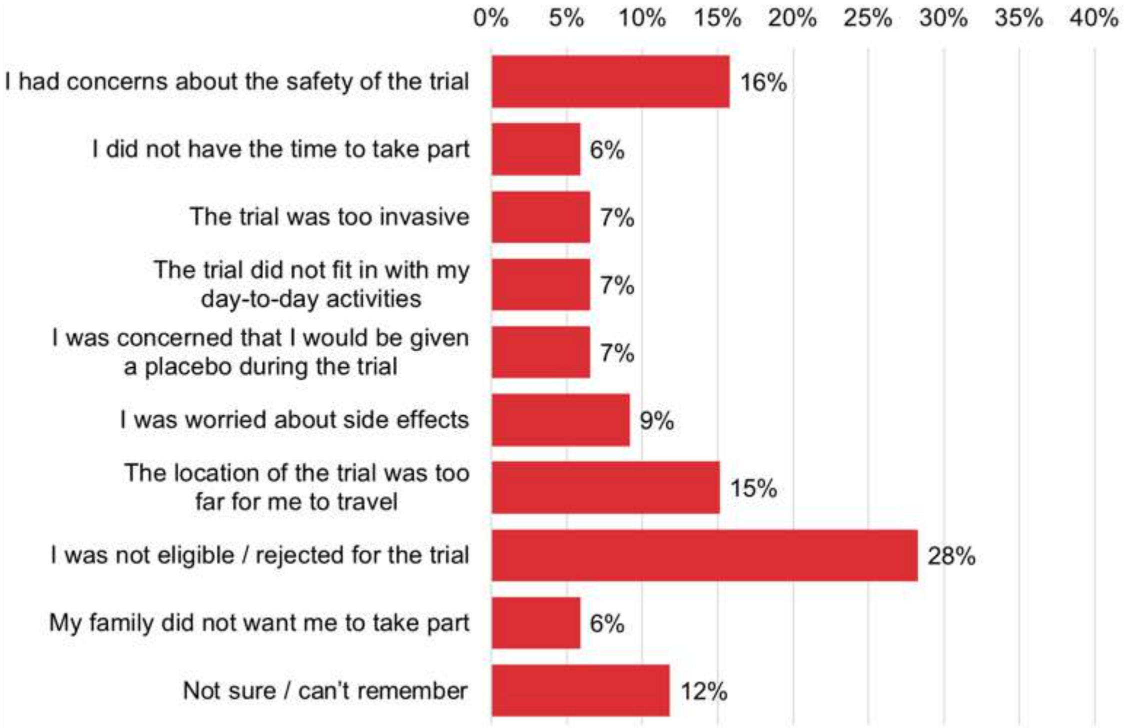

Figure 40: Reasons for not participating in a clinical trial

Clinical trials - age breakdown

The results also show that, with the exception of 16-24 year olds, the frequency of patients being given the option to participate in a clinical trial decreases as respondents get older.

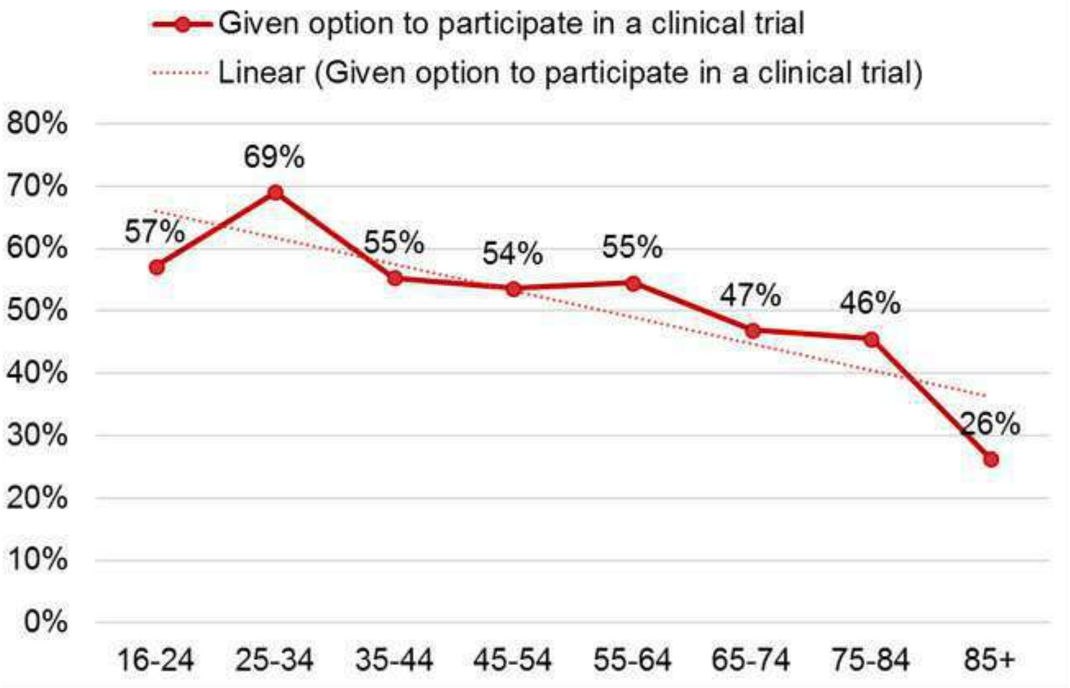

Figure 41: Given option to participate in clinical trial - by age group

Whilst older patients were less likely to be offered the opportunity to participate in a clinical trial they were just as likely to join the trial when offered.

It is interesting to note that the 16-24 group were the least likely to participate in a clinical trial, they were also more likely to say that they couldn't remember / didn't know why this was the case.

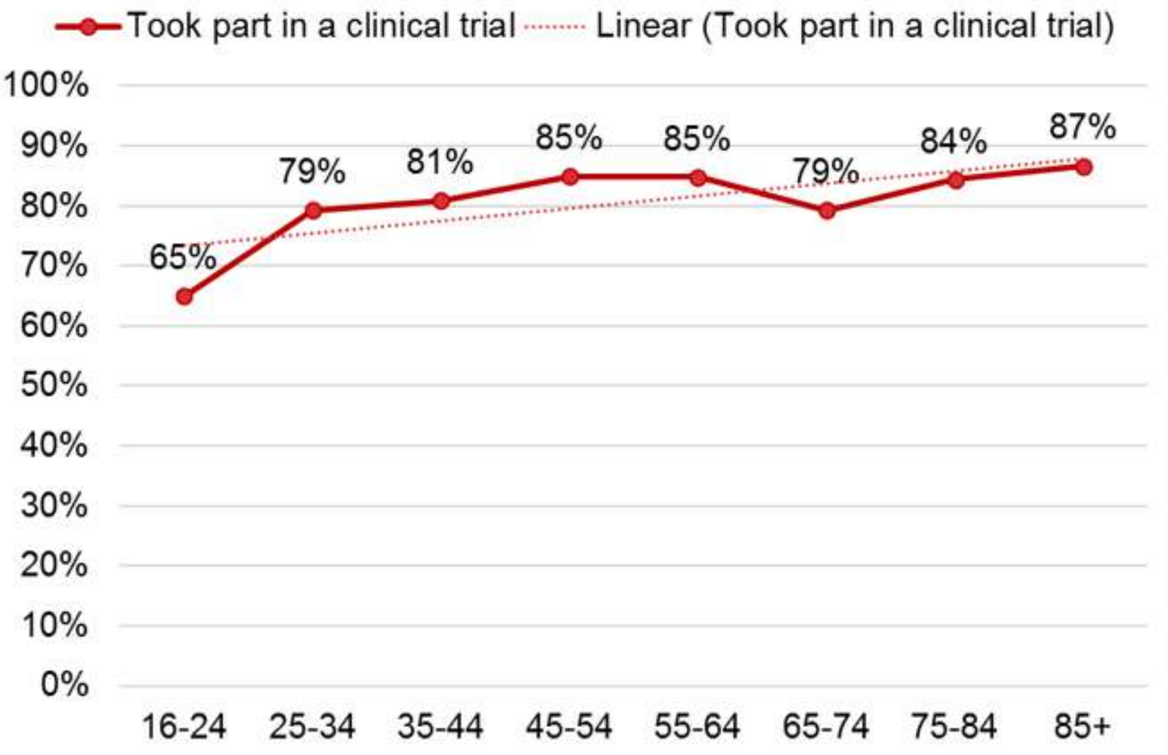

Figure 42: Offered a clinical trial and participated - by age group

These results are in part, included in Leukaemia CARE's report 'I Wasn't Born Yesterday', which recommends that patients of all ages should be given the option of joining clinical trials, so that the data provided is more representative of clinical practice.

http://www.leukaemiacare.org.uk/i-wasnt-born-yesterday

3.5 Living with blood cancers

Unlike other cancers, some types of leukaemia will not be cured during treatment, and patients will live with their cancer as a long-term condition. In this section of the questionnaire we asked respondents of their experiences of living with their blood cancer, including: pain and discomfort; impact of cancer on work / education, finances, travel and their emotional well-being.

3.5.1 Symptoms since diagnosis

We asked what symptoms respondents had experienced since their diagnosis.

The most frequently experienced symptom was fatigue 68%, followed by feeling weak or breathless 41%, and then sleeping problems 36%. 9% of respondents encountered no symptoms post-diagnosis.

Nearly all symptoms were reported more post diagnosis, and fewer patients reported having no symptoms. This could be due to the leukaemia having progressed, or that some of the ailments were actually caused by side-effects, and patients were unable to differentiate between them.

The chart below illustrates the full range of replies; comparing symptoms reported prior to diagnosis to symptoms reported post diagnosis, and also shows the frequency of matching side effects:

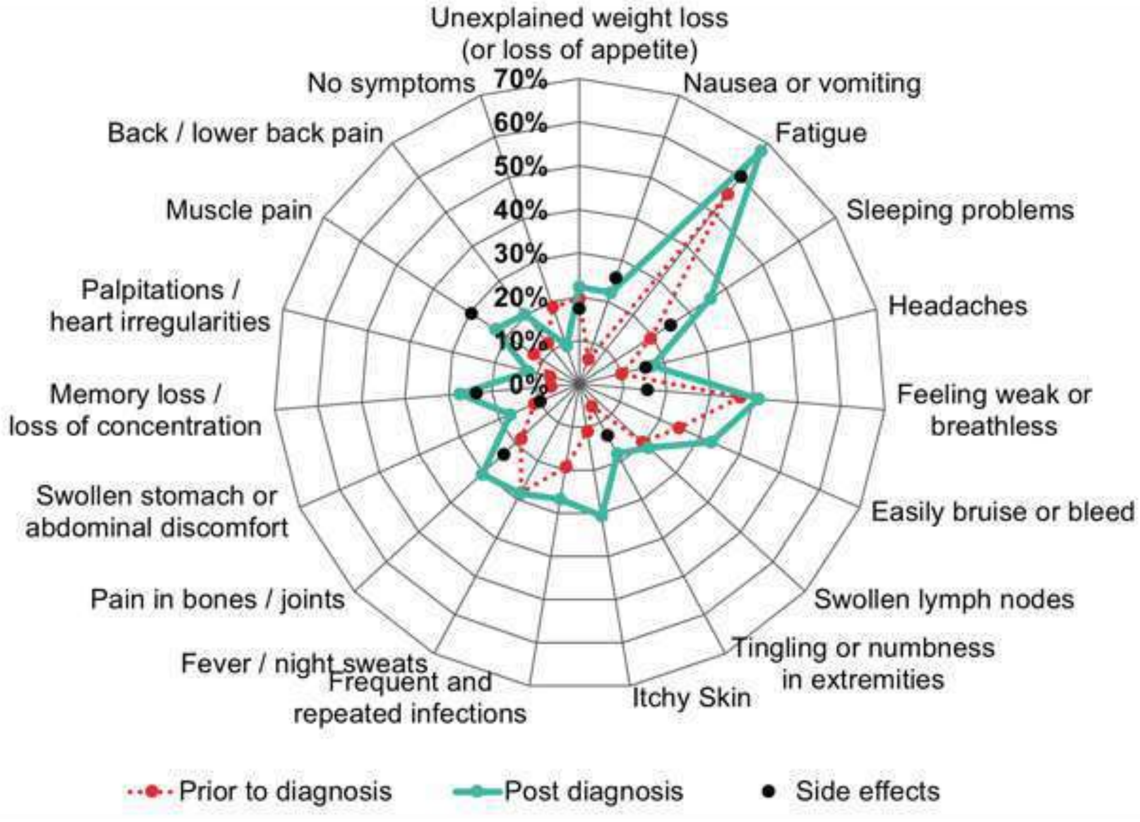

Figure 43: Symptoms reported prior to diagnosis vs symptoms reported since diagnosis

3.5.2 Pain and discomfort

Just over half of respondents (51%) experience pain as a result of their condition, 16% reported experiencing pain regularly and 5% constantly.

There was a difference between the experiences of the two respondent cohorts on this question. 62% of Arm 2 reported experiencing pain, compared to 46% of Arm 1.

CML respondents reported experiencing pain most frequently, followed by those with ALL, respondents with another type of leukaemia reported less frequent pain, as the chart below shows.

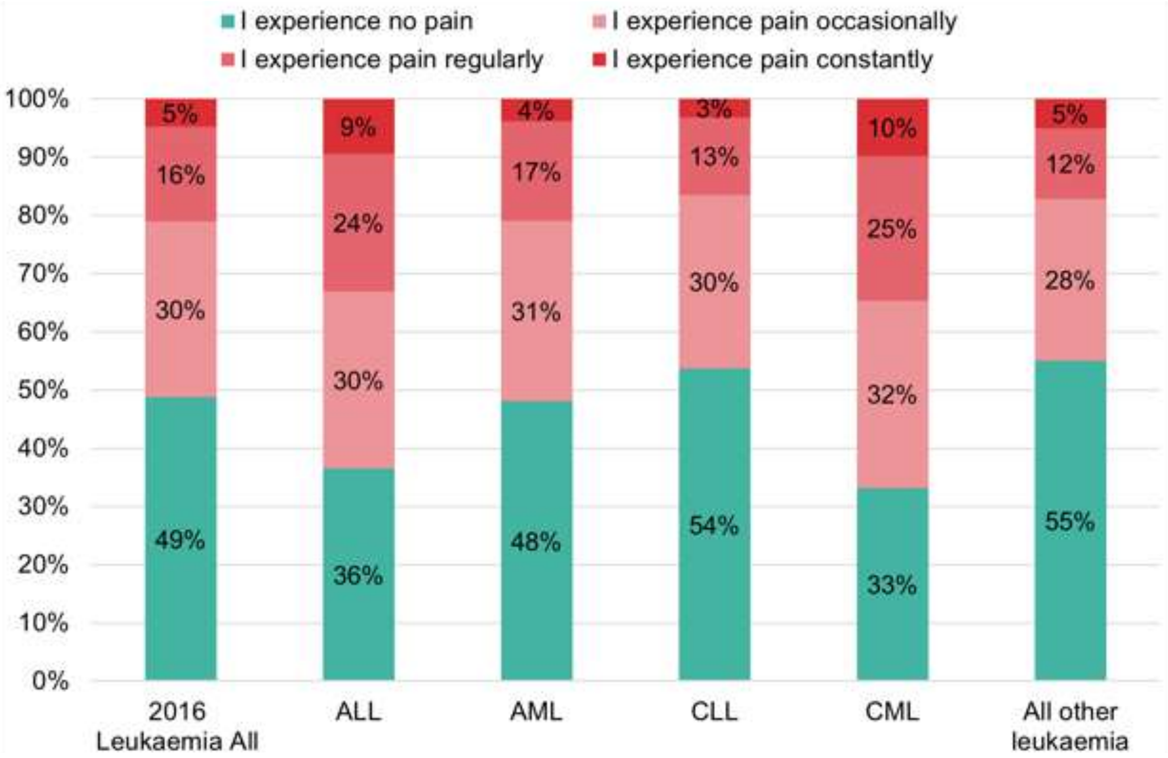

Figure 44: Frequency of pain experienced since diagnosis - by leukaemia type

3.5.3 Impact of cancer on movement

We asked respondents if their ability to move around had been affected by their blood cancer; on average 43% reported they experienced difficulty of varying frequencies. ALL patients were more likely to report an impact on their movement (61%), while CLL and those with another type of leukaemia were least likely (37%).

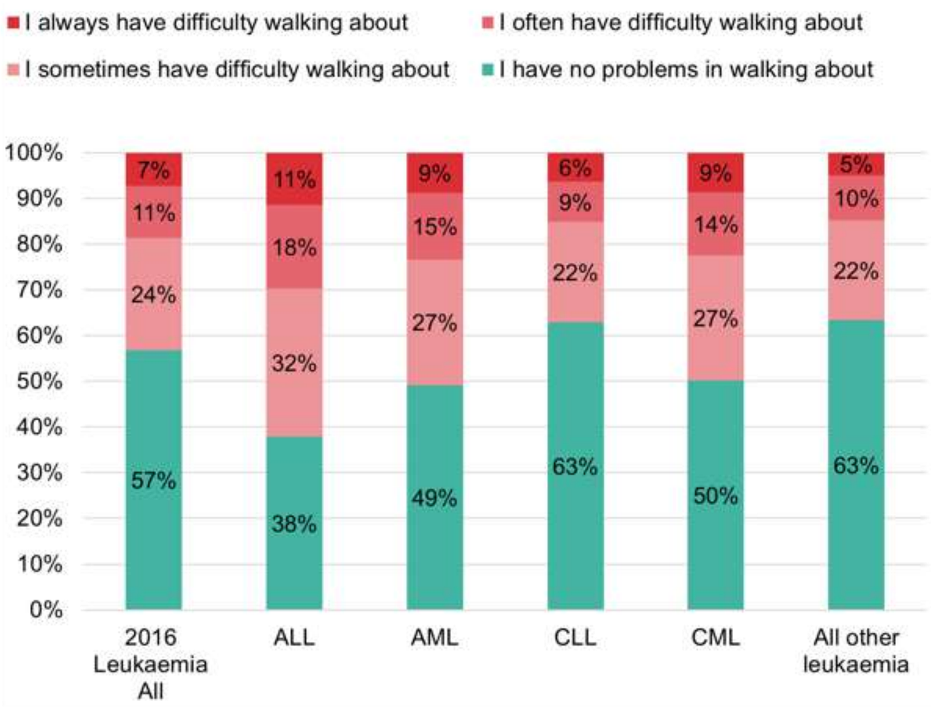

Figure 45: Impact of cancer on movement – by leukaemia type

3.5.4 Impact of cancer on work/education

We then asked if respondents' diagnosis had affected their ability to work or complete education. Of those respondents who answered this question 42% said that they were not in work or education before their diagnosis. The results below only include the people who were in work/education before their diagnosis.

Of the people who were in work or education, 59% reported that their diagnosis had an impact on this; over a quarter (26%) had to reduce their time in work or education and a third (33%) were no longer able to continue post diagnosis.

Respondents with ALL and AML were more likely to experience an impact on work/education, three-quarters of acute leukaemia patients had to stop or reduce their time in work or education.

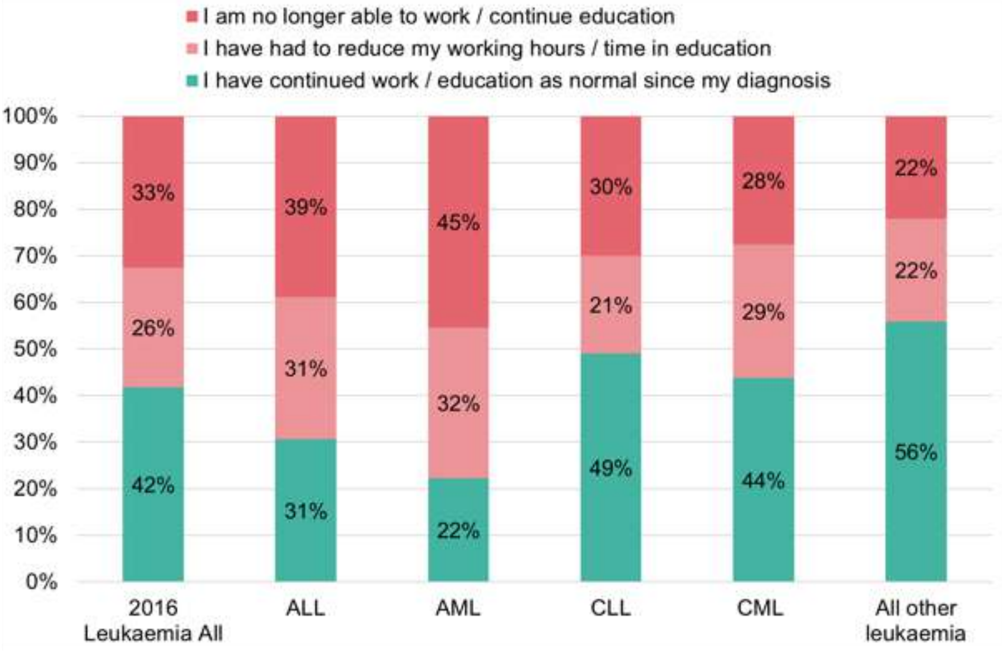

Figure 46: Impact of leukaemia on work/education - by leukaemia type

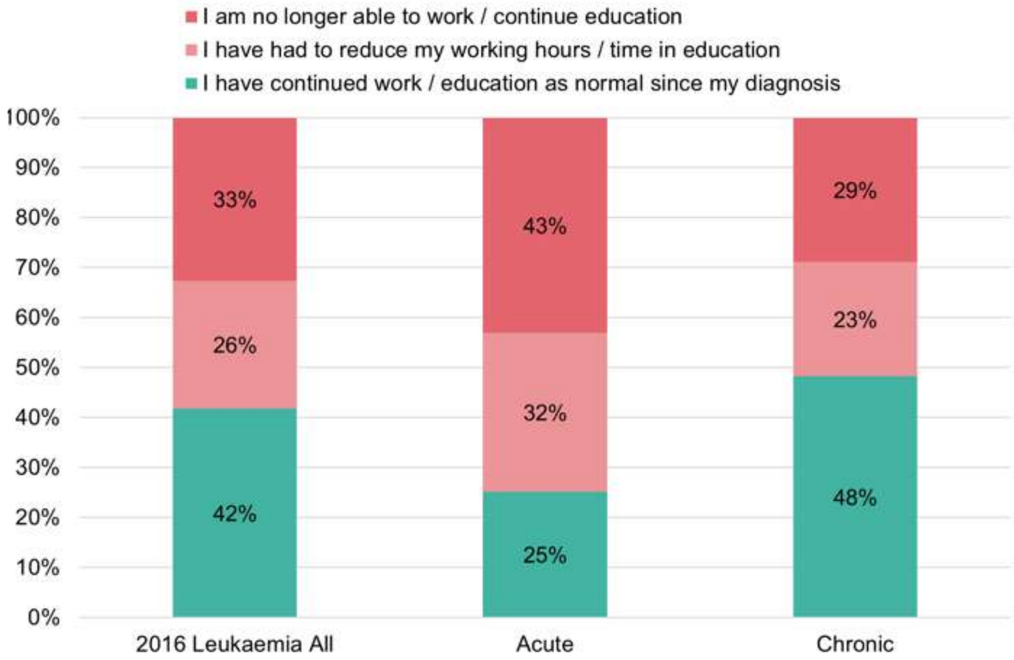

Figure 47: Impact of leukaemia on work/education - by acute and chronic leukaemia

3.5.5 Impact of cancer on daily routines

Respondents were asked if their diagnosis had affected their ability to perform their daily routines, such as cooking or cleaning. Those with an acute leukaemia were more likely to report an impact on their daily routines (65% ALL, 59% AML).

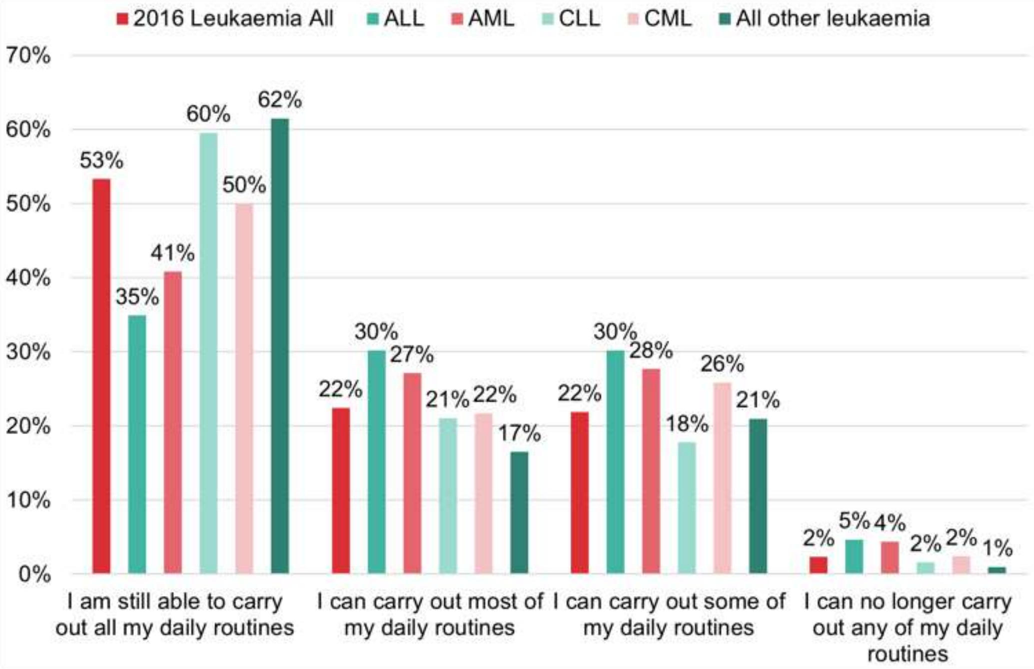

Figure 48: Impact of leukaemia on daily routines - by leukaemia type

3.5.6 Impact of cancer on self-care / independence

We also wanted to know if respondents' diagnosis affected their independence or ability to care for themselves. Overall across all leukaemia types, 72% of people said that this had not changed and 8% said that they often had difficulty or were unable to take care of themselves. ALL respondents were most likely to report an impact (48%), followed by AML (38%).

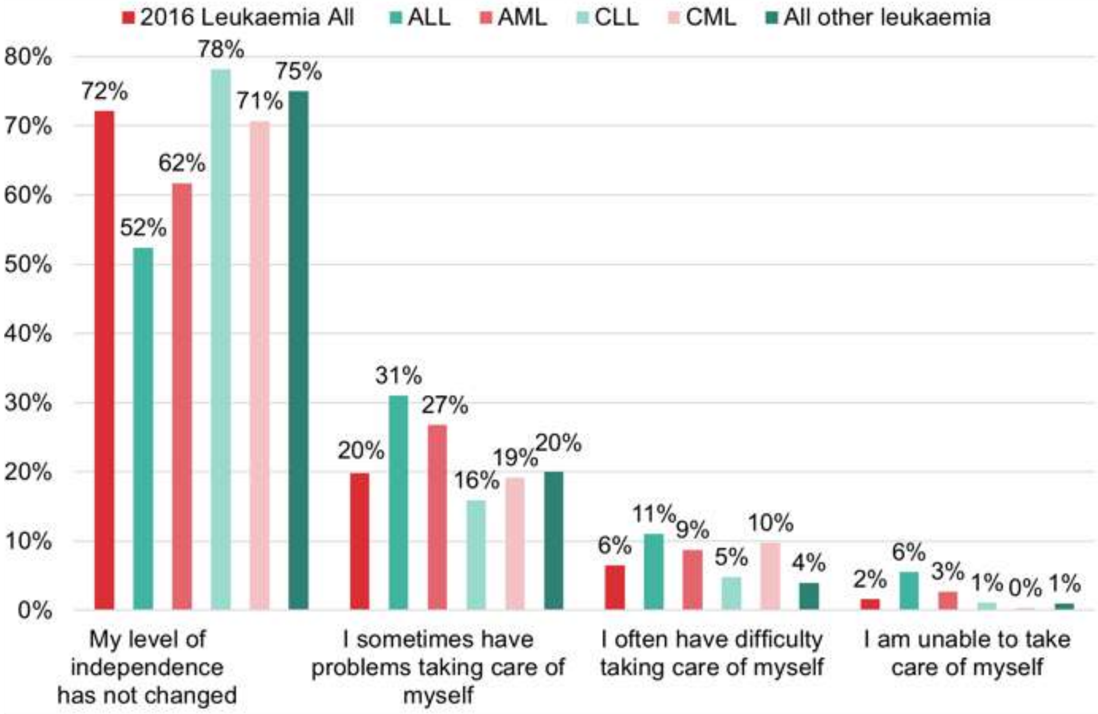

Figure 49: Impact of leukaemia on self-care/independence - by leukaemia type

3.5.7 Impact of cancer on finances

We asked respondents what financial impact their cancer had on them, 54% said they hadn't experienced any impact and 5% reported a positive impact, possibly due to reasons such as insurance pay-outs. However, 40% of people who responded to this question reported a negative financial impact: 37% of Arm 1 respondents reported a negative impact compared to 47% from Arm 2.

In addition, a larger proportion of respondents with an acute leukaemia reported a negative impact on their financial situation. This is likely due to these respondents undergoing, or having undergone active treatment and being affected by financial issues such as travel, childcare, and needing time off work.

One of the questions in the 2015 CPES asks if hospital staff gave information about how to get financial help or benefits they might be entitled to. 55% of leukaemia patients who would have liked this type of information were given it.

These results indicate that more work needs to be done to ensure leukaemia patients are given information on finances and benefits, or directed to a place where they can find it, to reduce the financial burden as far as possible.

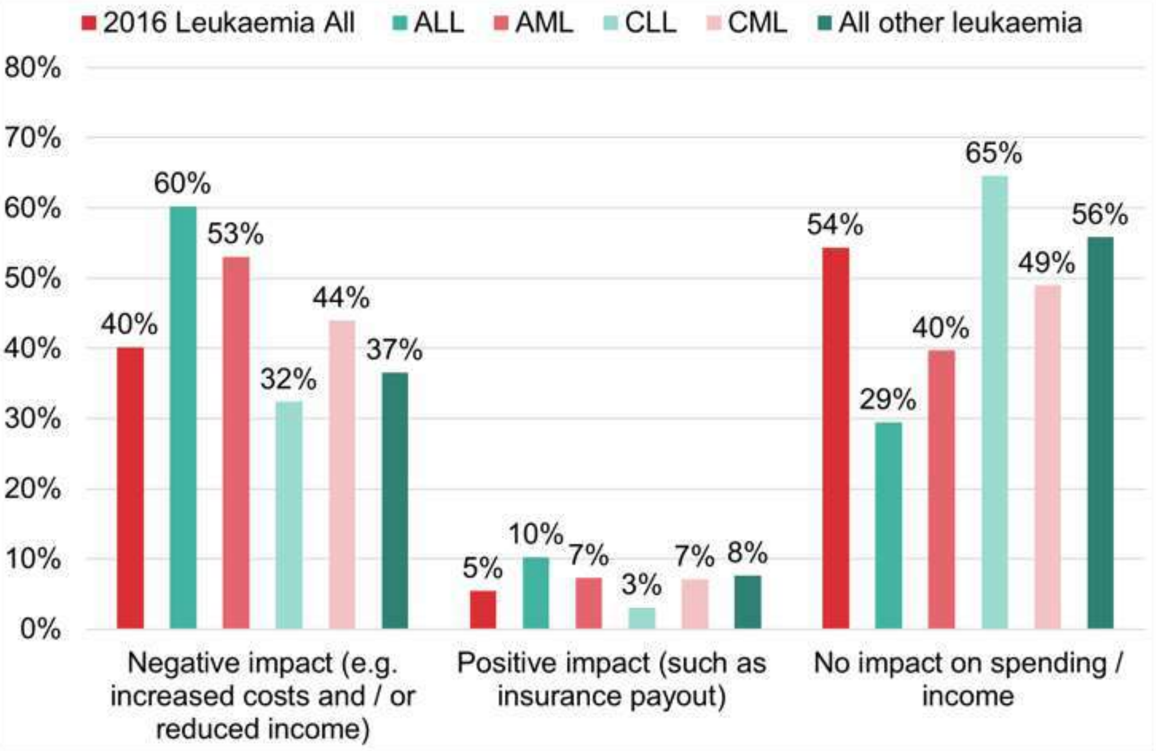

Figure 50: Impact of leukaemia on finances - by leukaemia type

"I felt financial judgements were made about me and did not ask if I needed financial help. The options should be explained carefully and more than once, as the drugs have strong effects." – [ALL patient, 55-64]

"Would like all the financial side and benefits entitled to, explained a lot more in depth and help into getting the right financial help as it's all so hard, stressful and worrying." – [AML patient, 25-34]

"Financial assistance, would be beneficial if someone would fill in and apply for all benefits available, as due to chemotherapy etc. makes it difficult to apply straight away, so lose out on benefits and much needed financial assistance. Car parking fees. Car parking availability." – [CLL patient, 45-54]

3.5.8 Impact of cancer on travel

We wanted to find out what impact cancer had on respondents' ability to travel. Understanding that there may be more than one impact, we asked them to select all options that were applicable to their situation. Over a third (34%) cited that the practicalities of travelling were more difficult and a fifth (20%) felt physically less able to travel.

Across leukaemia types, acute patients were more likely to feel less physically able to travel or choose not to do so. Chronic patients were more likely to say that their diagnosis had not impacted on their ability to travel. The practicalities of travelling had an almost equal impact on both acute and chronic respondents.

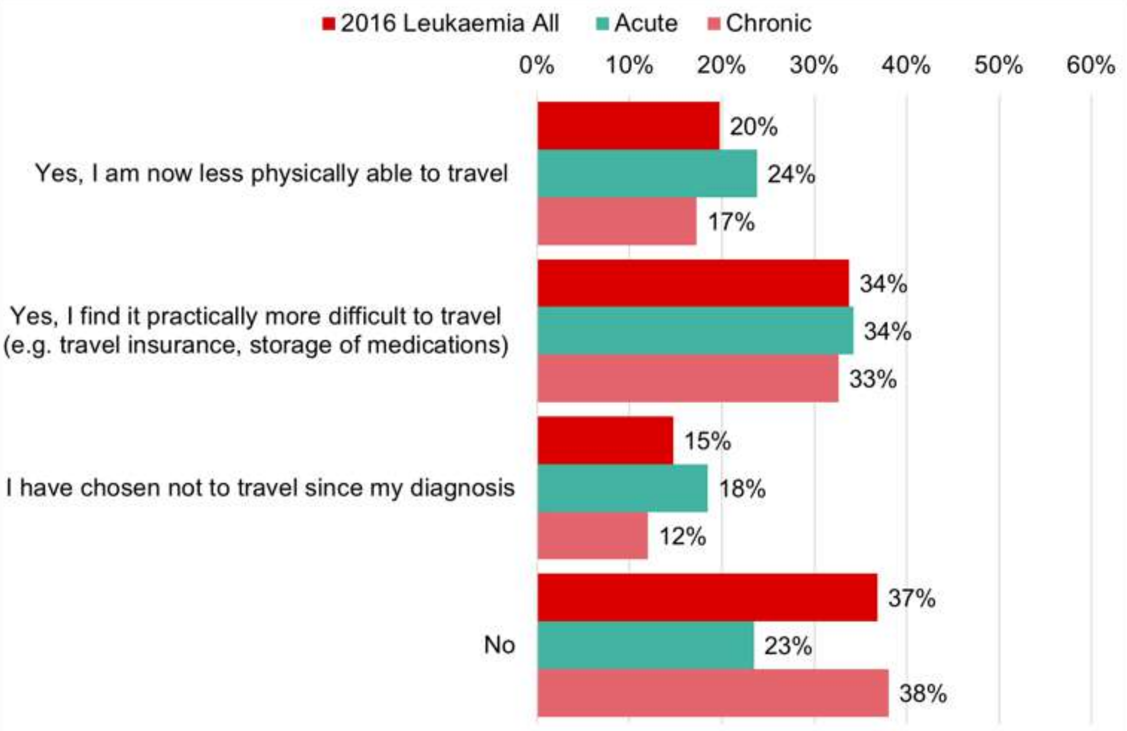

Figure 51: Impact of leukaemia on travel - by acute and chronic leukaemia

3.5.9 Impact of cancer on emotional well-being

We asked respondents how their emotional well-being had changed since their diagnosis. The responses show some clear differences on the emotional impact between the different types of leukaemia.

CLL respondents reported the least change (56%) while ALL reported most change (82%)

ALL and those within the 'Other leukaemia' category reported feeling more positive than other leukaemia types (23% ALL, 24% 'Other leukaemia'

ALL and CML reported the most negative change (ALL 60%, CML 55%)

ALL and CML were more likely to fee constantly depressed or anxious (6%)

There were also differences between the two arms of the survey. Respondents from Arm 2 were more likely to report feeling depressed or anxious more often since their diagnosis, (60%, compared to 39% Arm 1), and less likely to experience no change in their emotional well-being, (25%, compared to 42% Arm 1).

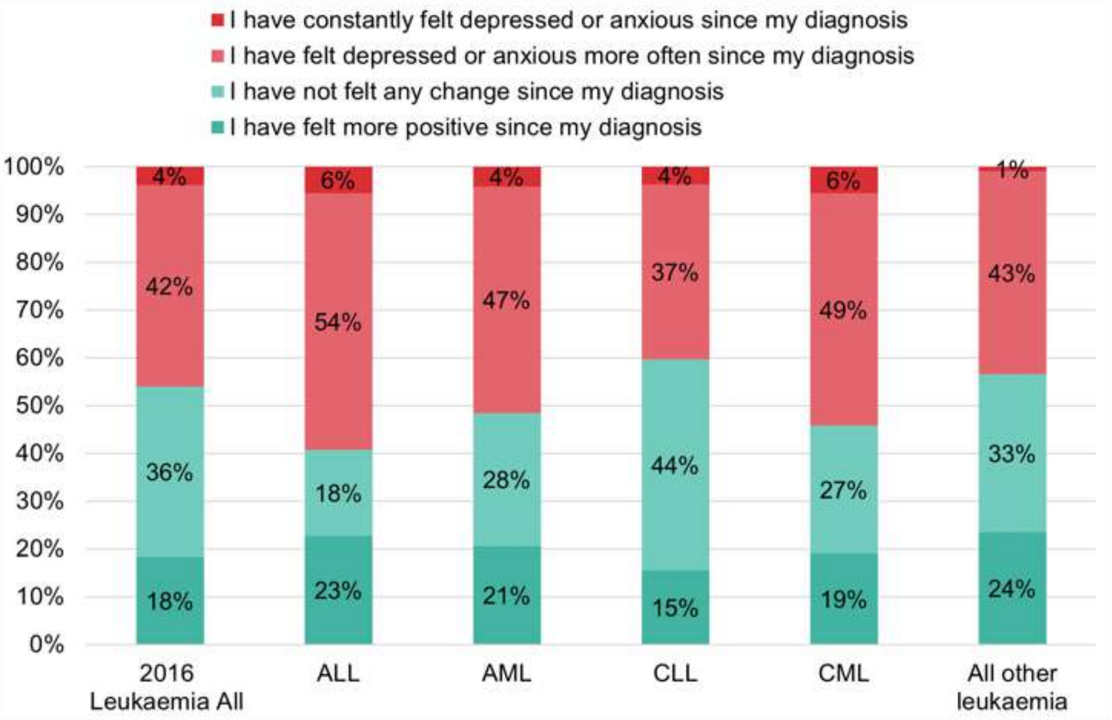

Figure 52: Impact of leukaemia on emotional well-being - by leukaemia type

Impact of cancer on emotional well-being - CLL breakdown

As CLL patients are more likely to be on placed on ‘watch and wait’, and continue to be monitored without active treatment for a longer period of time, we were interested to see if this had an impact on their emotional well-being.

As the chart below illustrates, CLL patients still on ‘watch and wait’ were more likely to say they were depressed or anxious since their diagnosis, when compared to patients who had started treatment (53% w+w, 37% started treatment).

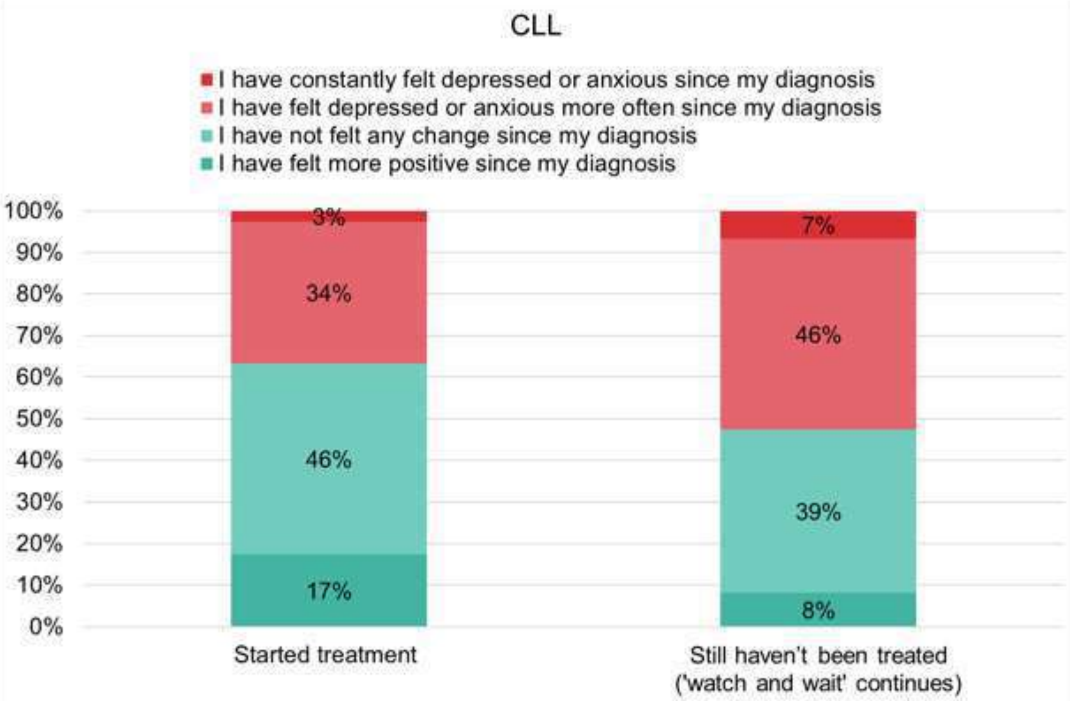

Figure 53: Impact of leukaemia on emotional well-being - by CLL respondents still on ‘watch and wait’

3.6 Support for people with blood cancers

In this section of the questionnaire we asked respondents about the support and information they were given during or post diagnosis. This included what information hospital staff gave them, when it was given, advice on finding further support, using the internet and quality of the information.

3.6.1 Information on support for people with blood cancers given by hospital staff

Initially respondents were asked if hospital staff gave them information about support or self-help groups for people with blood cancer. Of those people who wanted this type of information 78% said they were given it and nearly a quarter 22% were not. CML had the smallest percentage of patients given this information, whilst AML had the highest – 68% CML, 86% AML. Once again there was a distinct difference between the cohorts, 86% of Arm 1 were given information about support of self-groups, whilst just 62% of Arm 2 said this was the case.

GPs and consultants should point the way to support groups. Trawling the internet is not useful to the newly diagnosed. New patients should have a care / treatment / support pack that explains basic things such as what to ask at your next consultation. – [CLL patient, 55-64]

We then asked in what form respondents received this information. Whilst most patients said they were given both verbal and written information there was some variation between leukaemia types. CLL patients were less likely to be given both (58%) and more likely just to be given written information (31%) while 83% of ALL patients said they were given both verbal and written information.

We then asked at what points in their cancer journey information on support was given. Respondents could tick multiple answer options.

The results show that respondents predominantly received information on support during the early stages of their cancer journey and during treatment, with fewer patients reporting being given it after treatment. Respondents with a chronic leukaemia were more likely to be given information on support at diagnosis, and CLL patients had the highest percentage of respondents saying they were given information before they started treatment. Those with an acute leukaemia were more likely to get information during and after treatment, and to get this all throughout their cancer journey.

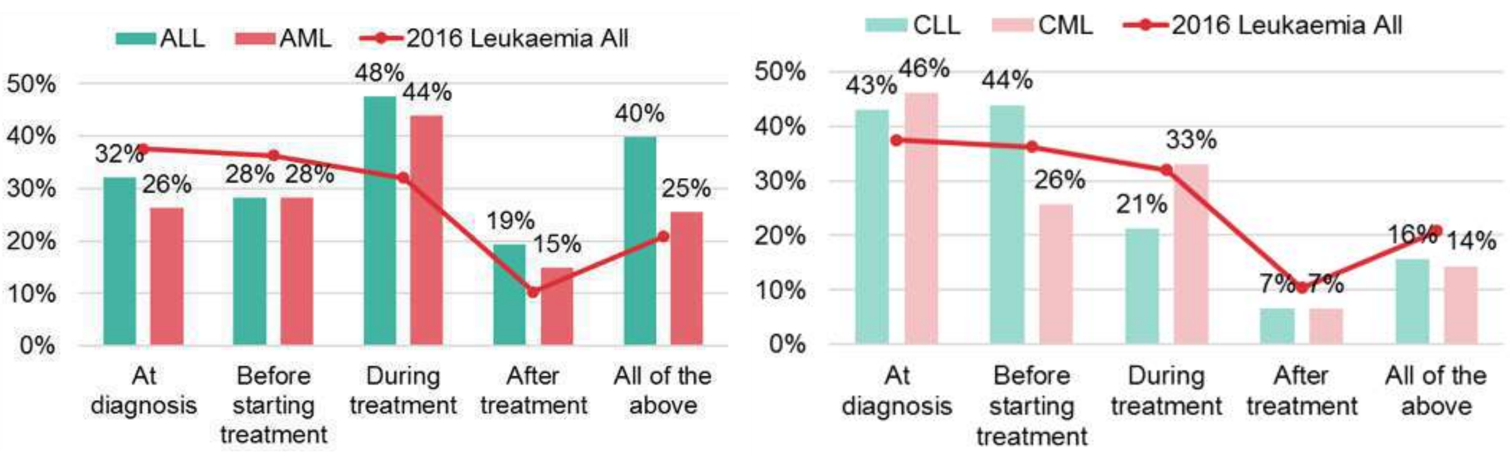

Figure 54: When information was provided - by acute and chronic leukaemia

On the whole respondents felt that the information they were given was consistent and of these nearly two thirds of respondents (66%) felt that the information was easy to understand and they understood all of it.

Between the leukaemia types, respondents with ALL were least likely to say they information they were given was easy to understand and that they understood it all (54%), they were also most likely to say it was difficult to understand and they did not understand most of it (5%).

3.6.2 Finding further information

Respondents were asked what the health professional who delivered their diagnosis said about finding further information. There were a range of responses and disappointingly the most common response was that the health professional didn't recommend anything (30% of respondents). 28% were told to come back to the hospital, 10% were recommended to contact Leukaemia CARE and 16% were recommended to another organisation.

Respondents from the online Arm 2 cohort were more likely to say that their health professional did not recommend anything (38%, compared to 25% Arm 1).

ALL respondents were least likely to say their health professional did not recommended anything (19%) with the other types ranging between 27%- 33%.

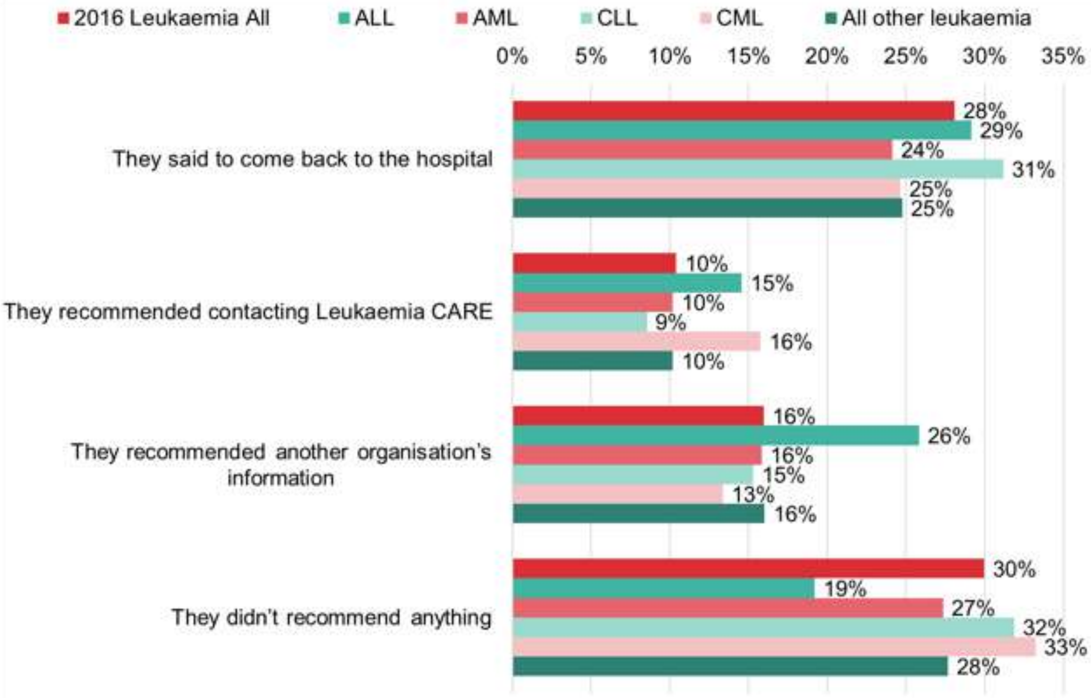

Figure 55: Recommendation of finding further information - by leukaemia type

3.6.3 Information from the internet

We asked respondents if their health professional made any reference to online information or the Internet. Overall, the majority of people (67%) said no, their health professional didn't say anything about the internet. 12% were told not to look at the Internet and not to trust online information, and 21% were told to look online but only at trusted websites.

We then asked if respondents had used the Internet to find further information, 61% said they had and 39% had not. Of those using the Internet, 83% found it useful, 10% did not find it useful and 8% thought the information was inaccurate or out of date.
Of the respondents who said their health professional didn't say anything about the internet, 55% reported they went on to use it. In addition, 61% of respondents said they used the internet, despite their health professional telling them not to look at it.

The chart below illustrates how useful respondents found information from the internet, in relation to what advice they were given by their health professional. Respondents whose health professional told them to look at trusted websites were more likely to find useful information. The results indicate that many patients will use the internet, regardless of what their health professional may advise, however the benefits they get are likely to be greater if they are advised to look in the right places. As such we feel it is imperative that Health Care Professionals give guidance to direct patients only to trusted websites, such as those of leukaemia charities.

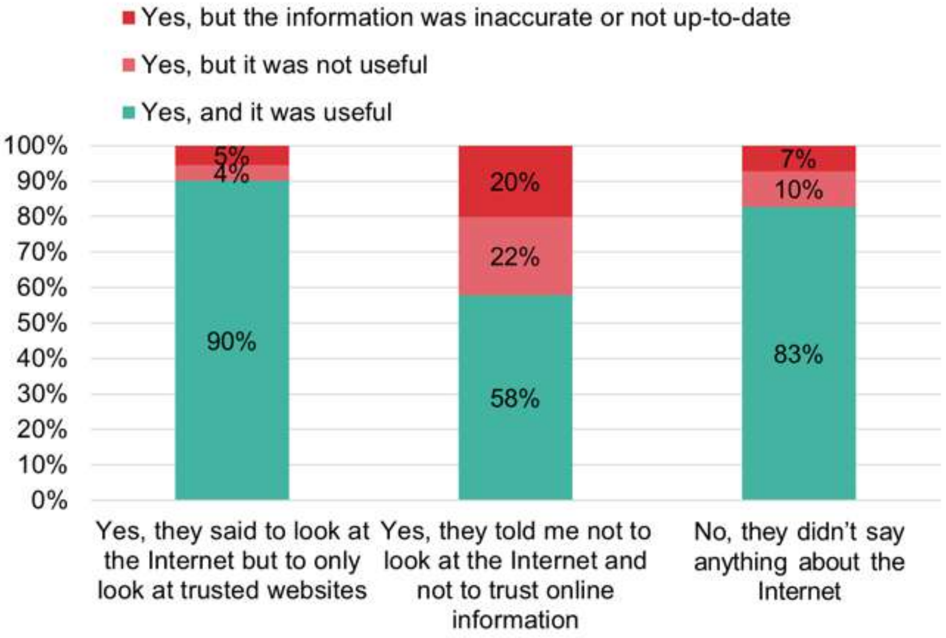

Figure 56: Usefulness of internet information - by advice given from health professional

"With the benefit of joining the CLL Association and following its website I have learned about treatments, understanding blood tests and how to live best to improve my prognosis." – [CLL patient, 65-74]

Information from the Internet - age breakdown

The older patients were, the less likely they were to be given guidance on using the internet. Interestingly the exception to this was within the 16-24 year olds, where 57% said they were not told anything about the internet. There could be a number of reasons for this; an assumption that they are an age group that will have little trouble finding information online, that they are receiving treatment in a paediatric setting, as younger patients they are being 'shielded' from certain information or that the information is given to their parents/guardians instead.

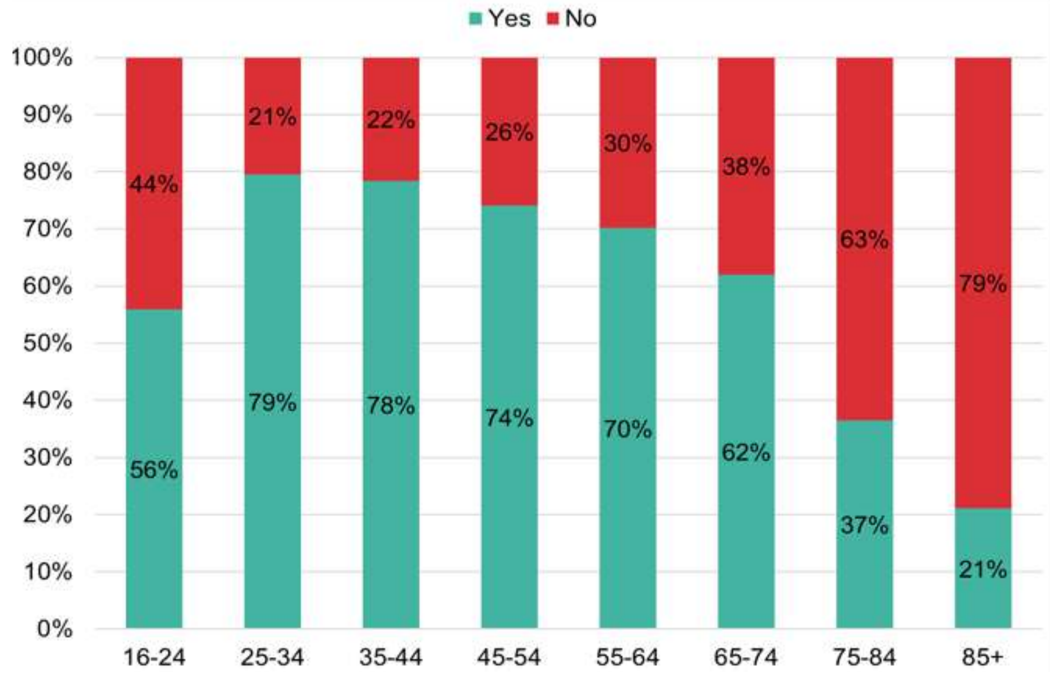

Figure 57: Health professional making reference to online information - by age group

Patients aged 16-24 and over 65 were much less likely to use the internet to find further information.

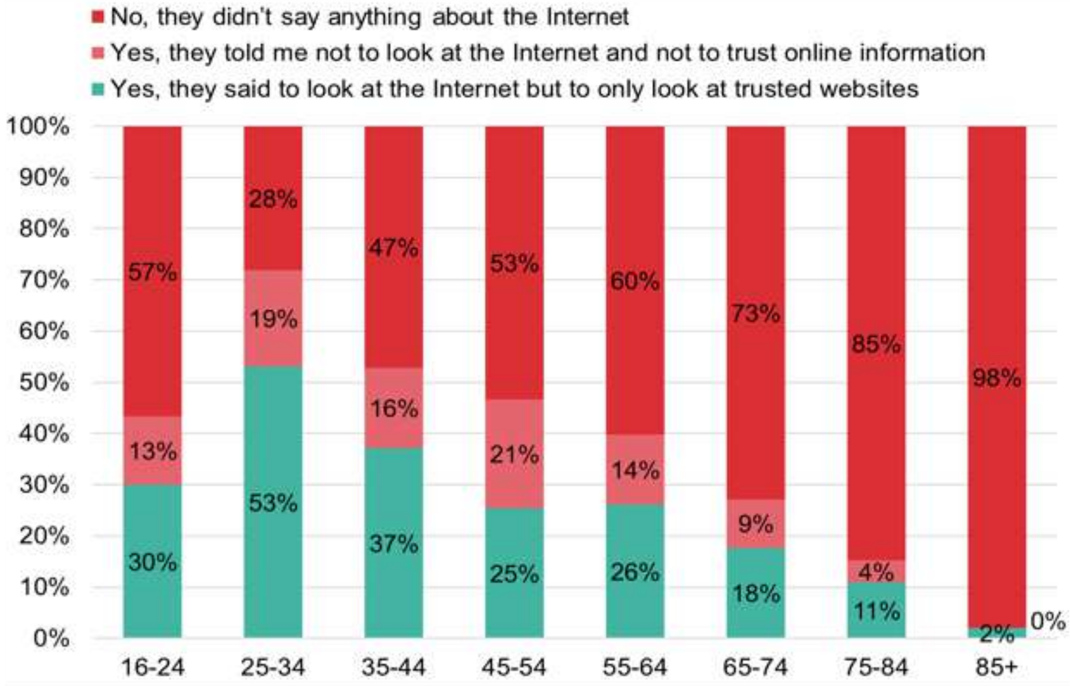

Figure 58: Respondents saying they used the internet to find further information - by age group

However, the older respondents were, the more likely they were to report finding information from the internet useful.

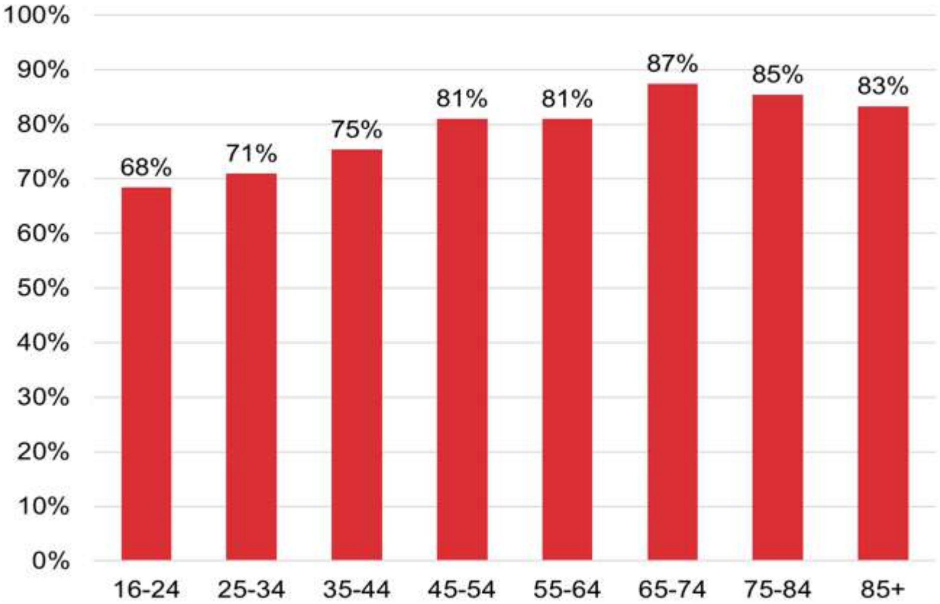

Figure 59: Respondents saying they found information on the internet useful - by age group

These results are included in Leukaemia CARE's report 'I Wasn't Born Yesterday', which recommends the need for more guidance on using the internet and verified websites for all ages.

http://www.leukaemiacare.org.uk/i-wasnt-born-yesterday

3.6.4 Additional sources of support

We asked respondents to tell us if they received support from the organisations listed below. And select as many options as were applicable to their circumstances.

Respondents from Arm 2 were more likely to say they had not received support from their hospital's own services and more likely to have received it from all other sources listed. Arm 2 reported being more likely to say they didn't need support, but where they did receive non-hospital support Macmillan was the most frequently used.

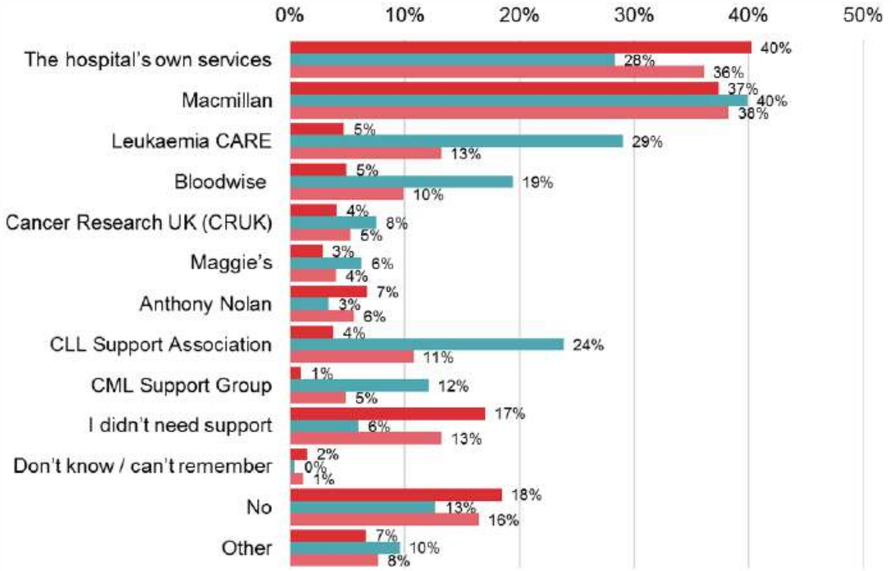

Figure 60: Had support the following organisations - by patient cohort

3.6.5 Overall views of information given

Overall 89% respondents said the quality of the information they were given was either good, very good or excellent. The full breakdown can be seen below:

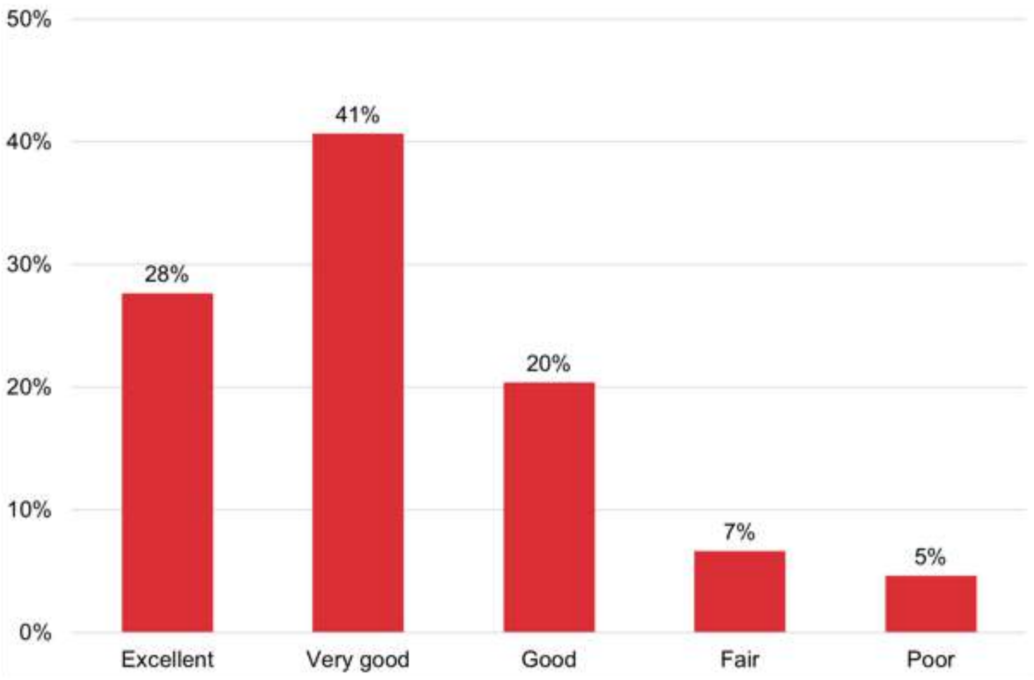

Figure 61: Rating of quality of information given

3.6.6 Additional areas / types of support

We were interested to understand if respondents were offered any additional support in areas such as buddying or being given access to a Clinical Nurse Specialist (CNS). We asked respondents to select all additional support options they had been offered.

There is some distinct variation in the experiences being reported between the different leukaemia types, and some interesting results around the provision of Clinical Nurse Specialists.

A smaller percentage of respondents with a chronic or 'other' type of leukaemia were offered counselling or psychotherapy compared to their acute counterparts.

8% of CLL respondents said they were given details about support groups, compared to over double this (17%/18%), in the other leukaemia groups.

On average, 38% of respondents said they were given access to an CNS. Considering that 85% of leukaemia patients who replied to 2015 CPES said they had been given the name of a CNS who would support them through their care, and 91% said they found it easy to contact their CNS, it is surprising that our results are so low in comparison.

There are clear differences in provision between the leukaemia types: 49% of ALL and 45% of AML respondents reported that they were given access to a CNS, compared to 36% CLL and 33% CML. In addition, of those respondents who said they were still on 'watch and wait', just a quarter said they had been given access to a CNS (24% in CLL patients).

"Specialist nurses do not always have experience of all cancers and concentrate their work on the patients who are suffering from acute cancers with chronic disease being relegated because of urgency and time limitations." – [CLL patient, 65-74]

"On seeing a doctor, when I asked about a support nurse/link nurse, I was sharply told that I would only be allocated one when treatment commences!" – [CLL patient, 55-64]

Overall, 41% of respondents said they had not been offered additional support, however around a quarter of acute patients said this (26%/27%) compared to 44% and 47% of those with a chronic leukaemia.

The message coming through is that there are clear gaps in the provision of support to leukaemia patients, in particular to those with a chronic type.

It has been established that the presence of a CNS is a powerful and positive influence on a cancer patient's experience and therefore it is disappointing to see that this support does not appear to be being made available across all leukaemia types and treatment paths.

"I have had wonderful care from day one. Having a named person I could contact for advice was the best thing, hardly ever needed to, but the assistance was there." – [AML patient, 55-64]

"The CNS nurse was invaluable." – [AML patient, 25-34]

Full results can be seen in the chart below:

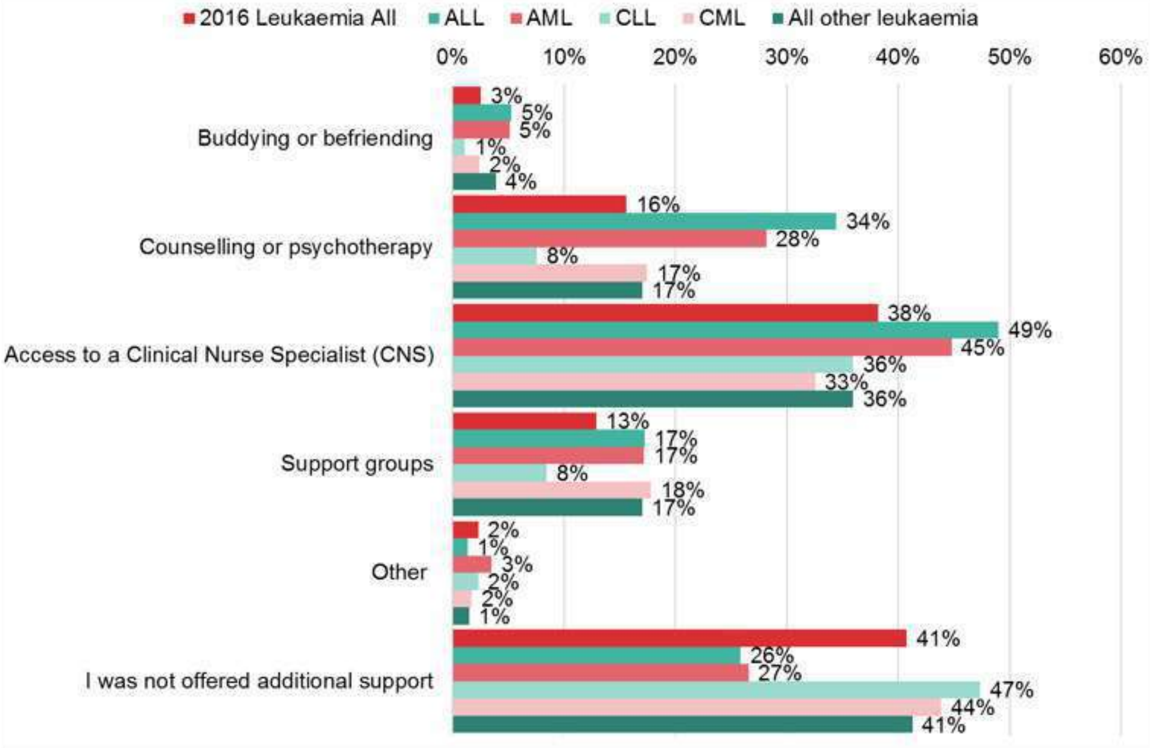

Figure 62: Offered additional support - by leukaemia type

3.6.7 Impact of information and support on treatment choices

Overall, 70% of respondents accessed the support and of these 84% reported that it helped them feel better or more positive. It is interesting to note that nearly a third (30%) didn't access this support. Despite chronic patients being less likely to have been offered support, they were almost as likely as acute patients to access it, as the chart below illustrates.

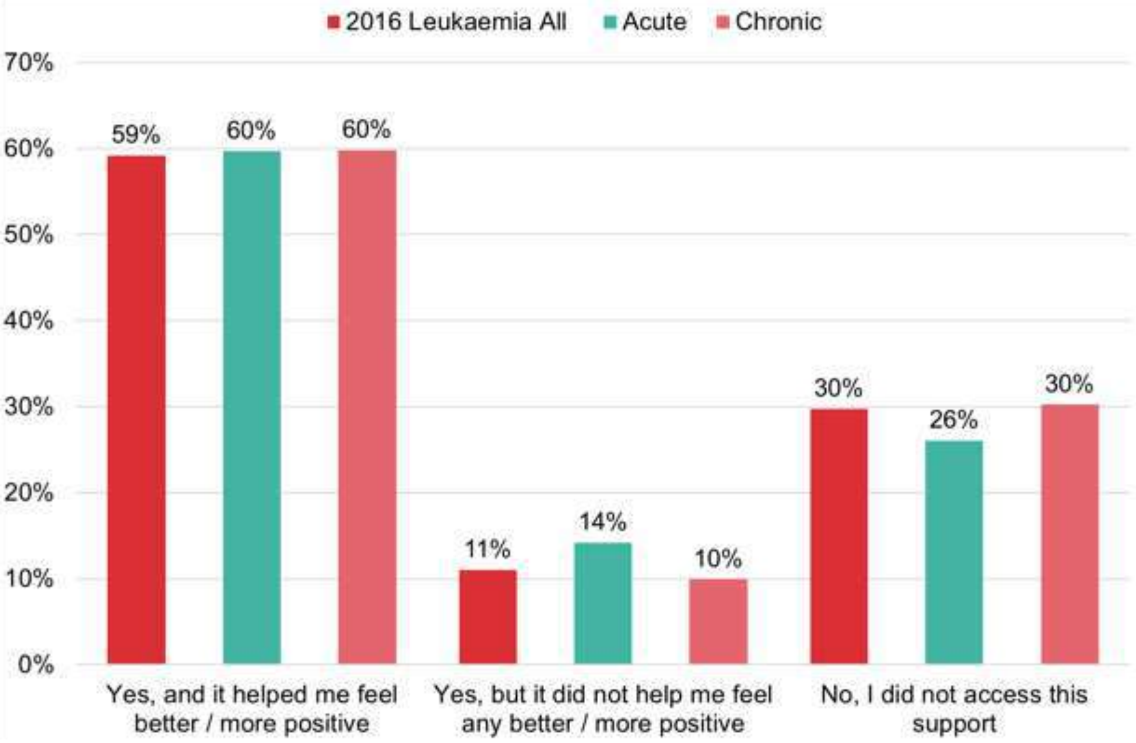

Figure 63: Accessed additional support - by acute and chronic leukaemia

We asked if the provision of information and support had an impact on respondents' treatment choices. 79% of respondents didn't feel their choices had been affected.
Of the small number of people who reported their treatment choices had been affected by provision of information, the majority (41%) said that because of the provision of information they chose a specific form of treatment.

"I requested a drop in dose level which was agreed." – [CML patient, 65-74]

The full breakdown is below:

7% requested / insisted on a delay in their treatment

11% requested / insisted they be treated more quickly

41% Chose a specific form of treatment

5% refused a specific form of treatment

35% said there was another reason

3.7 Care from GP after diagnosis

This section looked at the care provided to patients from their General Practitioner (GP) since diagnosis.

3.7.1 Were GPs given enough information from hospital

We asked whether respondents thought their GP was given enough information about their condition and treatment they had received at the hospital. Most respondents (89%) said that their GP was given enough information.

Respondents from Arm 2 were less likely to think their GP was given enough information about their condition and hospital treatment (80%, compared to 93% Arm 1).

In addition, significantly fewer CML patients reported that this happened, 77% compared to the other types of leukaemia which ranged between 90%-93%.

3.7.2 GPs and nurses at local surgery as sources of support

We asked respondents if they thought that GPs and nurses at their general practice did everything they could to support them during their cancer treatment. Two-thirds of respondents (67%) said that they regularly saw their GP and wanted this type of support; the majority of these (45%) said that they thought their GP practice definitely did all they could to support them. However, 12% felt more could have been done and nearly one fifth (19%) said that their GP practice was of no help or support to them.

Between leukaemia types, the response for those saying their general practice was of no help or support ranged from 15% (CLL) to 26% (CML).

There is a clear difference in experiences between Arm 1 and Arm 2 respondents. As might be expected, Arm 2 (containing people who have reached out for support from Leukaemia CARE and other charities/support groups) report much poorer provision of support from their GP practice - as the chart below illustrates:

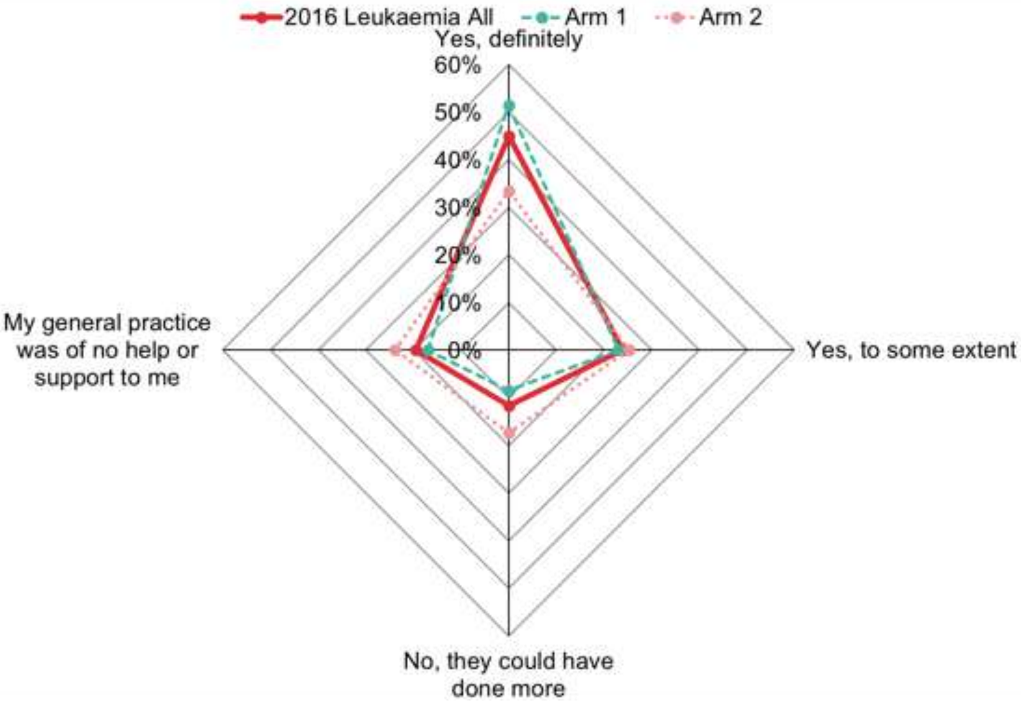

Figure 64: Given enough support at general practice during cancer treatment - by patient cohort

"Feel GP care lacking - week after completing chemotherapy got bad cold and sinus problems - went to doctors when not better in 4 weeks - never checked my chest or anything - no medication - bearing in mind low immune system could turn nasty felt no assistance whatsoever. Perhaps in copy letter to GP's consultant could mention that extra care should be given to coughs, sinus problems, chest problems etc. Good care at hospital but no confidence in GP care - feel isolated." – [CLL patient, 55-64]

3.7.3 Nature of support from GPs

Where support was provided, we asked respondents about the nature of that support – we asked them to select all the options that were applicable.
It is reassuring to see a large number of respondents (84%) said that their practice had access to their hospital records and understood what treatment they had received. However apart from this, very few respondents received any kind of practical support; such as a support plan or even signposting to other sources of information and support.

Between the two arms of the survey those from Arm 2 were less likely to say their GP practice had access to their hospital records and understood the treatment they had received but more likely to say that their GP practice had signposted them to other sources of information and support.

There were some small differences between the different types of leukaemia:
ALL respondents were more likely to say their GP practice had access to their hospital records and understood what treatment they had received (90%), compared to those who did not have one of the main four leukaemia types (81%)

ALL and 'Other leukaemia' respondents were more likely to say their GP/practice nurse discussed and agreed a support plan (11%), those with a chronic leukaemia were least likely to say this was the case (CLL 7%, CML 6%)

AML and CLL patients were more likely to say their GP/ practice nurse discussed the signs and symptoms associated with a recurrence or relapse (7%)

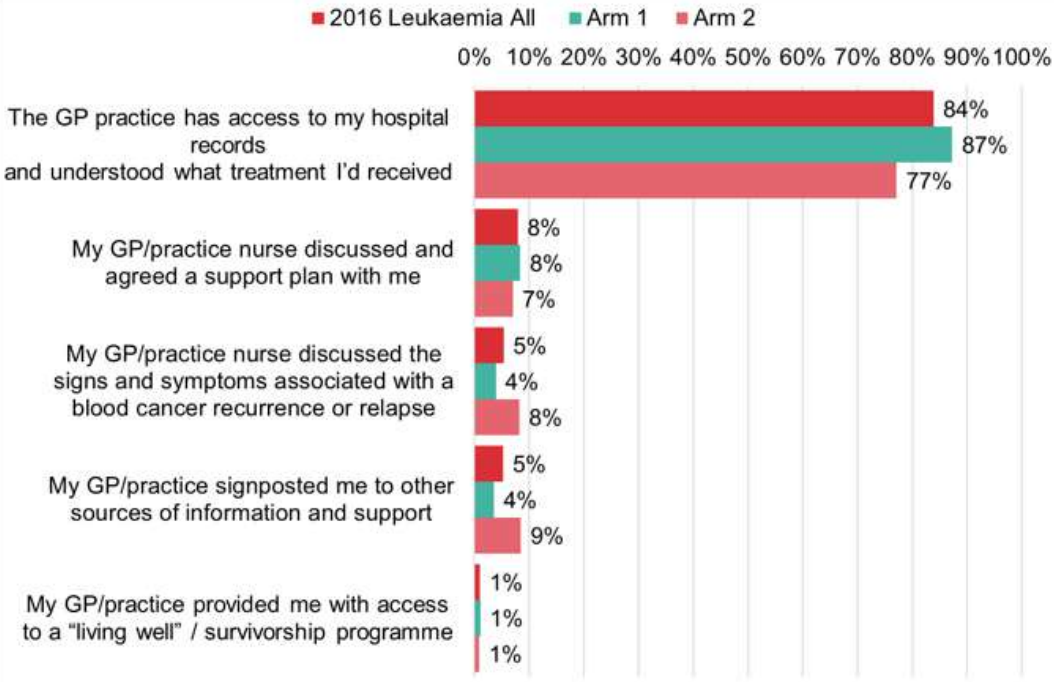

Figure 65: Nature of support given by general practice - by patient cohort

"I changed GP practice ...they are more helpful in terms of access at times of infection, though there has been no discussion of my treatment plan." – [CLL patient, 65-74]

We asked those respondents who said their GP surgery had not given them any help or support to explain further by chosing one or more of the answers below. Of the 244 respondents who said this was the case, the most common experience reported was that there was no discussion about their Leukaemia diagnosis and treatment within the GP practice (70%). In addition, 27% of respondents said they were not signposted to any other information and support and 18% felt that despite some discussion about their diagnosis and treatment no practical support was offered.

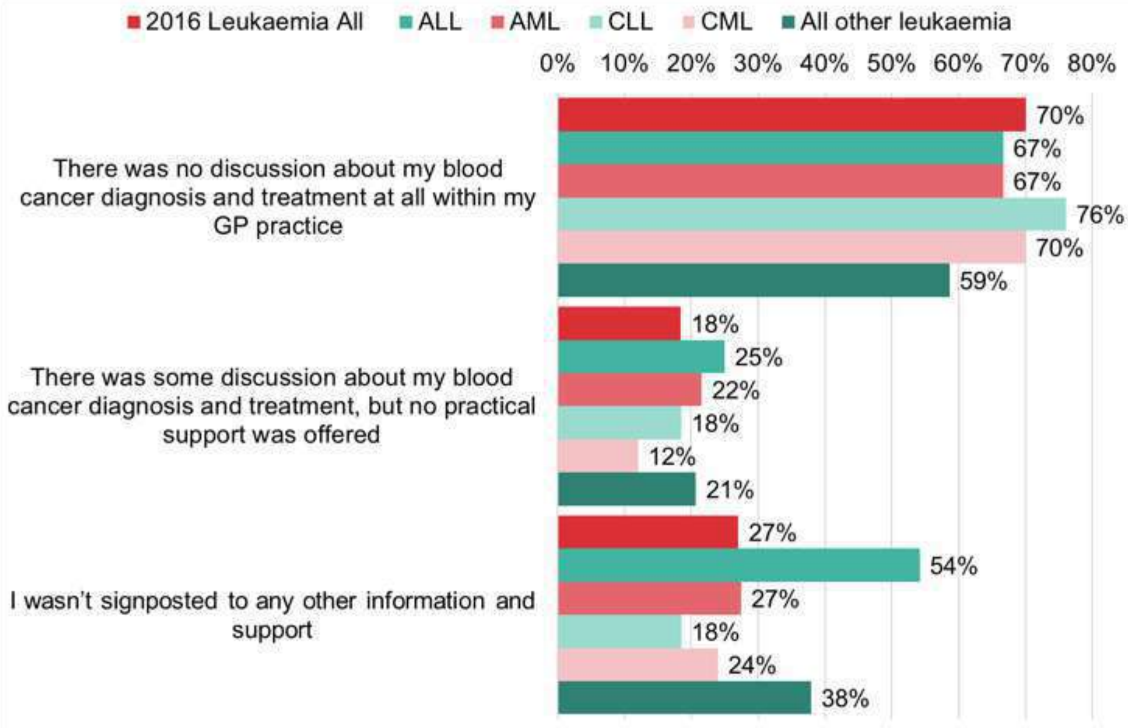

Figure 66: Reasons general practice was of no support - by leukaemia type

"The GP service however I feel let me down. My GP has never mentioned my treatment to me unless I have brought it up." - [Other leukaemia patient, 25-34]

3.8 After treatment

This section of the questionnaire looked at the respondents' cancer journey after initial treatment, including if they had relapsed and stem cell transplants.

3.8.1 Relapse

Patients were asked if they had experienced a relapse, and if this was the case how many times this had occurred.

ALL – 13% had relapsed - 72% once, 0% 4 or more times

AML – 28% had relapsed - 80% once, 2% 4 or more times

CLL – 30% had relapsed – 53% once, 14% 4 or more times

CML – 16% had relapsed – 54% once, 22% 4 or more times

Other leukaemia - 25% had relapsed – 77% once, 2% 4 or more times

In addition, patients who reported experiencing a relapse were more likely to say they felt more depressed or anxious since their diagnosis, this was true across all the different leukaemia types, al the chart below illustrates:

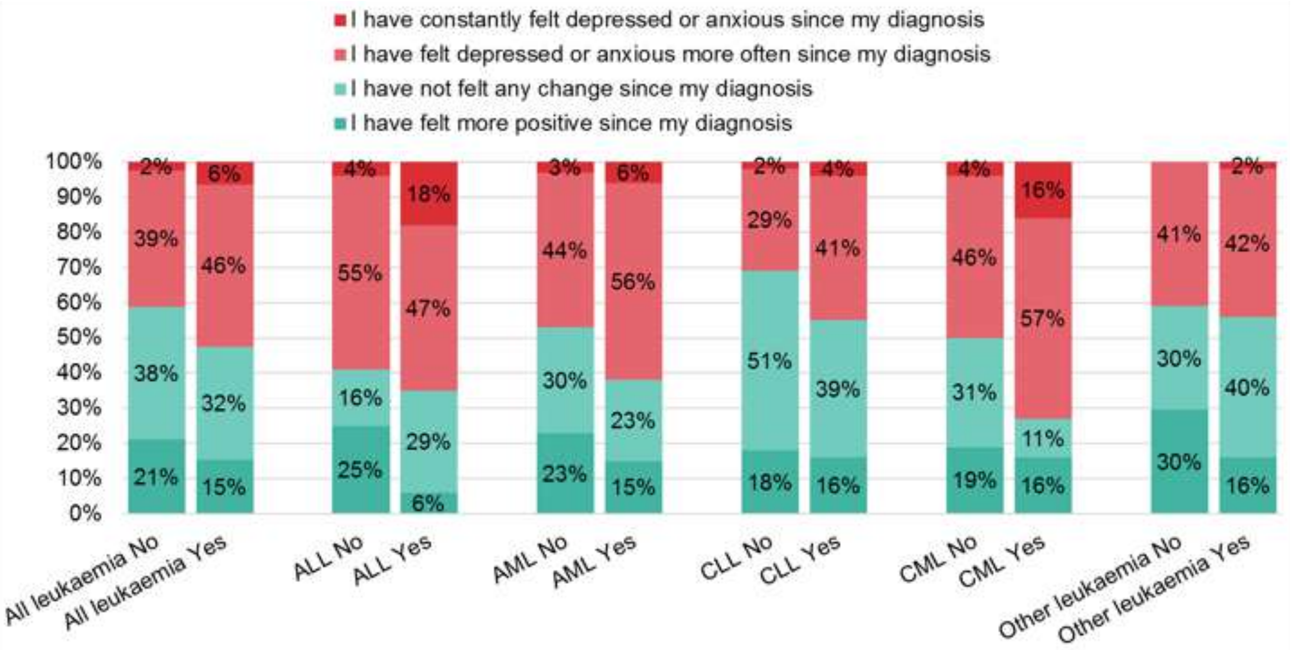

Figure 67: Impact of leukaemia on emotional well-being - by leukaemia type and relapse status

3.8.2 Stem cell transplants

We asked respondents if they had a stem cell transplant as part of their treatment for blood cancer. As there was the possibility patients may have had both an autologous and an allogenic cell transplant, we asked them to select all options that were applicable to their circumstances.

As the chart below illustrates, patients with an acute form of leukaemia were much more likely to have had a stem cell transplant, and autologous stem cell transplants are much less frequent than allogenic.

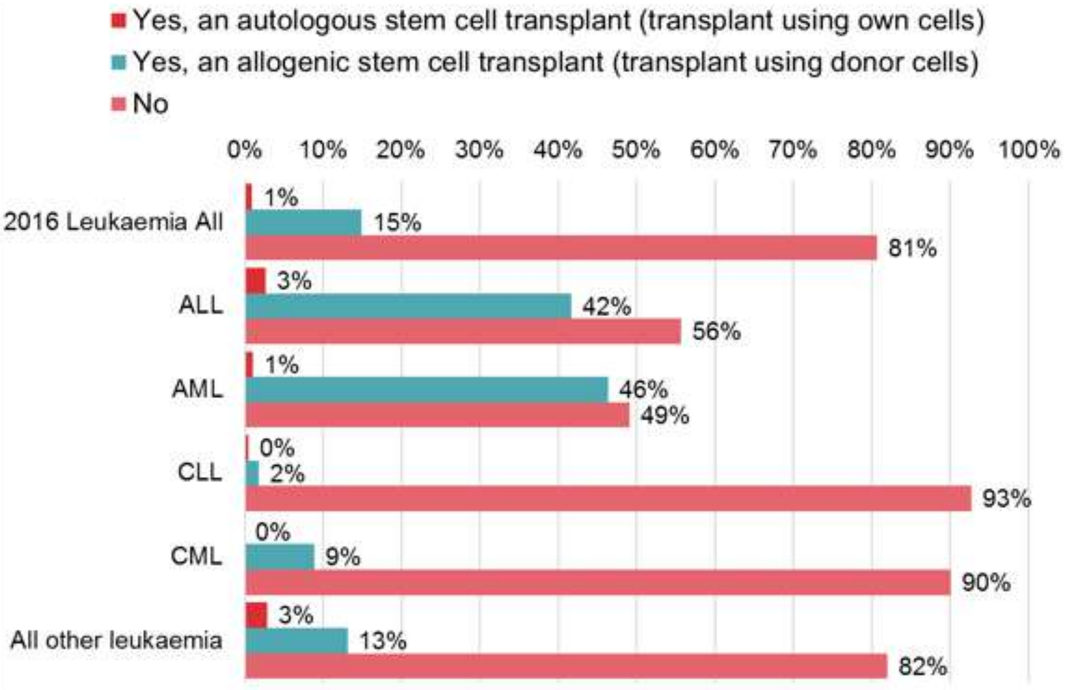

Figure 68: Had a stem cell transplant - by leukaemia type

3.9 Testing and monitoring

Leukaemia patients often undergo regular testing and/or monitoring to assess their response to treatment. In this section of the questionnaire we asked about the frequency of tests, how results of tests were delivered and experiences of bone marrow biopsies and aspirations.

3.9.1 Respondents undergoing regular testing / monitoring

In the first instance respondents were asked if they were regularly undergoing testing or monitoring.

As would be expected a very high proportion of people (97%) were undergoing regular testing or monitoring.

Across all leukaemia types, for the majority (47%) this was happening every 3 months and 25% said it took place every month. 7% of respondents said testing/monitoring was variable. However, as the charts below demonstrate, there is variation depending on the type of leukaemia.

Figure 69: Frequency of monitoring - by leukaemia type

Frequency of testing or monitoring - time since diagnosis breakdown

Using responses from patients who gave a year of diagnosis we looked at the occurrence and frequency of testing over time.

Acute leukaemia

86% of acute leukaemia patients diagnosed between 5-10 years ago and 68% of those diagnosed over 10 years ago reported they were still having regular testing and monitoring. Due to the small number of respondents within this group it is not possible to draw definitive conclusions around the frequency of testing over time. However, the small amount of data gathered suggests that testing and monitoring occurs more frequently in the earlier years since diagnosis, decreasing in frequency over time.

Chronic leukaemia

99% of chronic leukaemia patients diagnosed between 5-10 years ago and over 10 years ago said they were still undergoing regular testing or monitoring.

All age groups have a similar proportion of patients being tested/monitored at each time-point

Patients diagnosed 0-3 years ago were slightly more likely to be tested/monitored every month, compared to the other groups, and less likely to be checked once a year

Patients diagnosed over 10 years ago were least likely to report being tested every month, and one of the groups more likely to be tested once a year

The majority of all groups were being tested/montitored every 3 months, between 44%-52% said this was the case

Less than 10% for all groups said the frequency of monitoring was varied

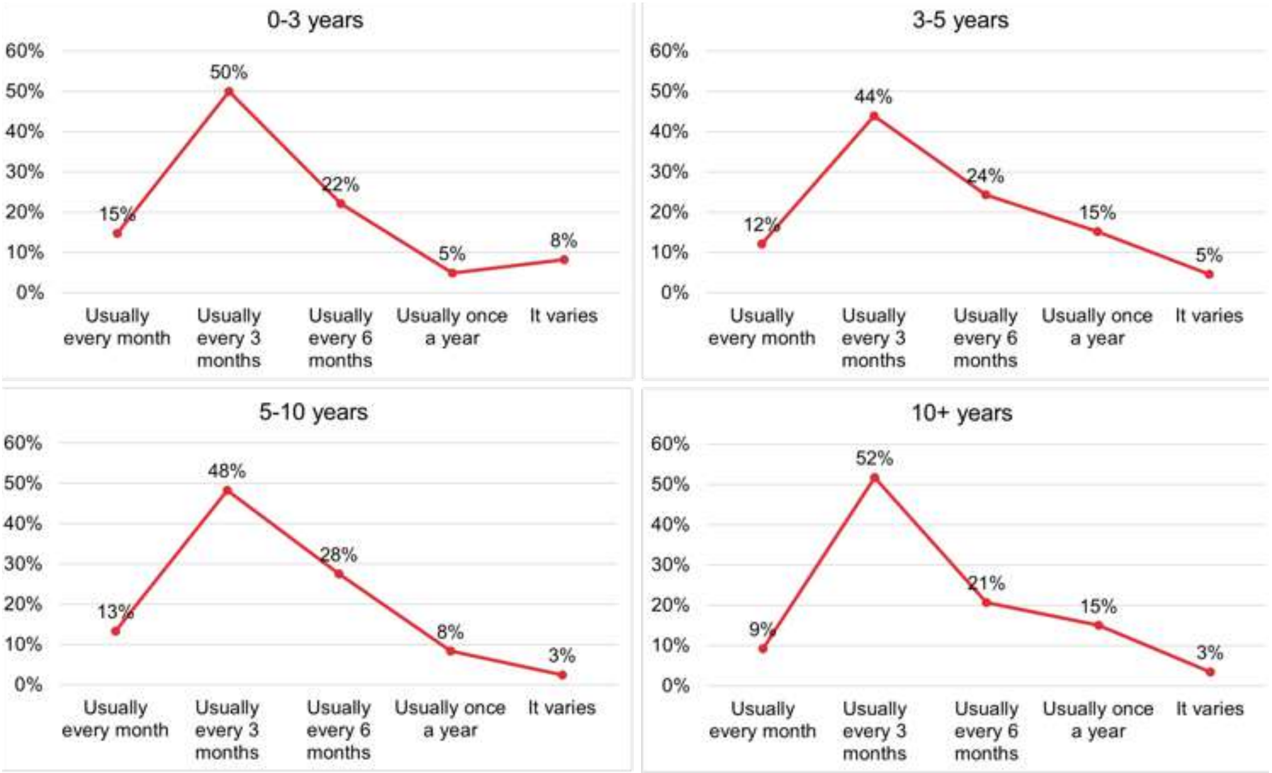

Figure 70: Frequency of testing or monitoring - by time since diagnosis – chronic leukaemia patients

3.9.2 Explanation of results from testing / monitoring

Nearly three quarters (74%) of respondents were given a complete explanation of their rest results, 11% of respondents had to ask for an explanation, 3% did not receive an explanation but would have liked one and just 1% said they didn't receive an explanation but they also didn't need/want one.

CML patients were least likely to report being given a complete explanation without having to ask (63%). In addition, both CML and CLL respondents were more likely to want an explanation of their results and not to be given one – 4% compared to 0% - 2% within the other cancer types. Nearly a third (31%) of respondents said that they were not given a copy of their test results to take away, but that they did not want/need these. This ranged between 25% and 37% across the different leukaemia types.

Of those respondents who wanted a copy of their test results, around two thirds said they could get these, although as the chart below shows, some still had to ask. The exception to this is within CML, where over half of patients didn't get a copy of their test results, but would have liked to.

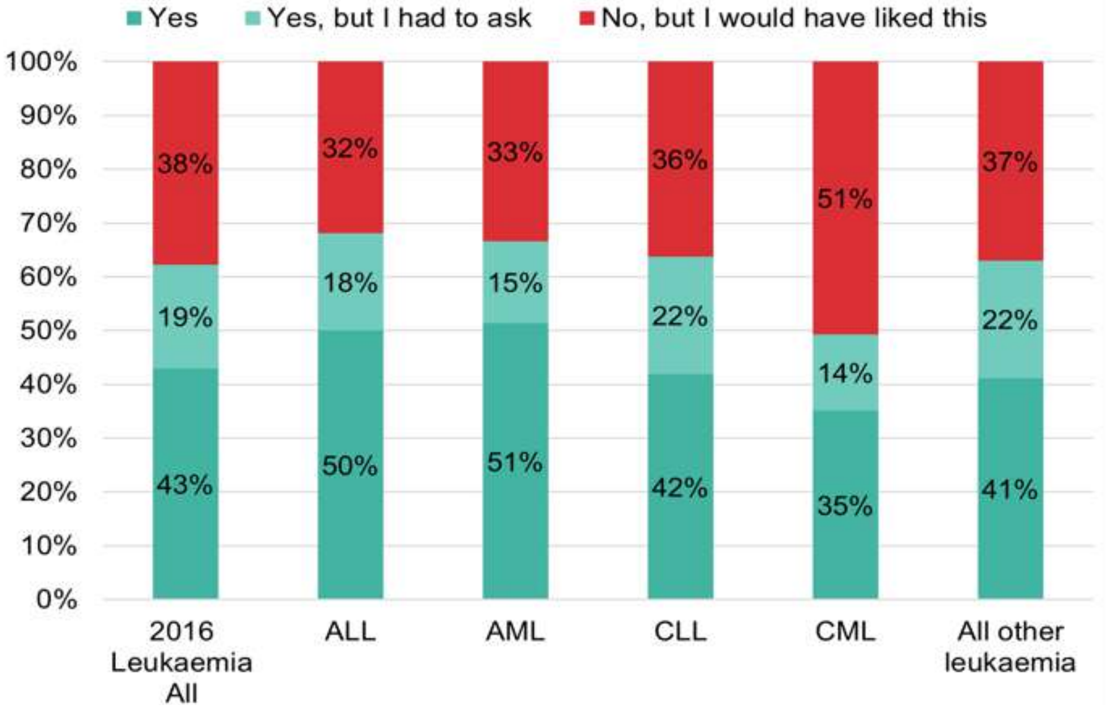

Figure 71: Given a copy of test results - by leukaemia type

"I would also like the option of receiving my results via email or the ability to view them via a secure website. It feels like I am being a nuisance when I chase them for my results." – [CML patient, 35-44]

3.9.3 Respondents undergoing bone marrow biopsy / aspiration

Overall, 79% of respondents had either a bone marrow biopsy or a bone marrow aspiration. In comparison to the other types of leukaemia 35% of CLL respondents had not undergone either procedure.

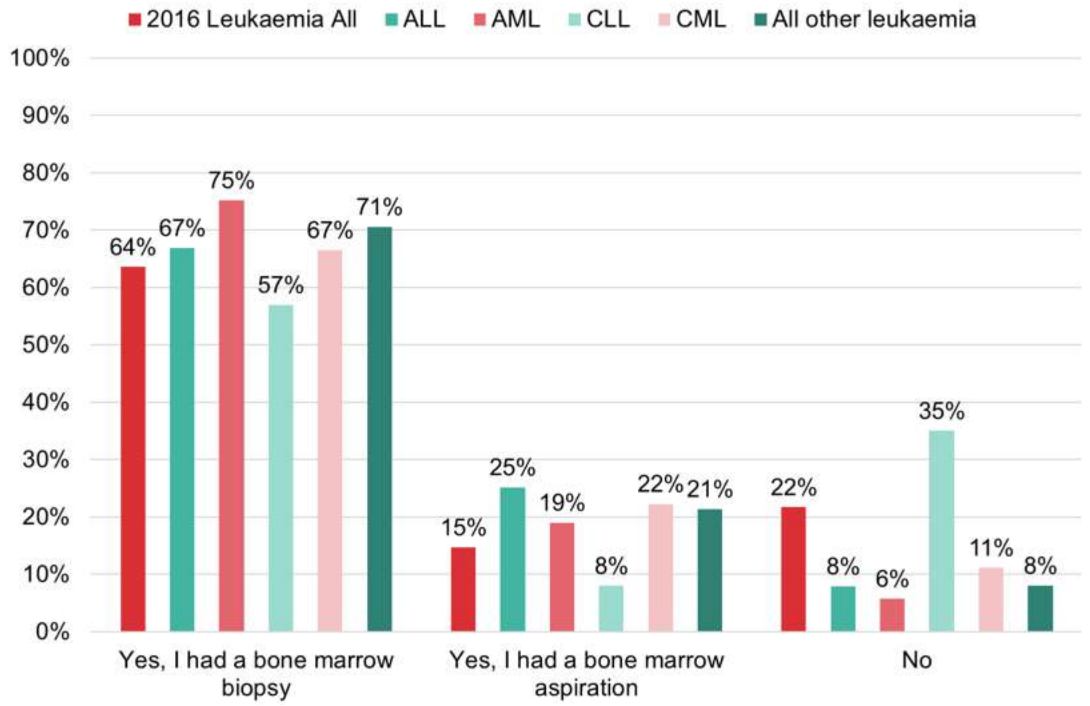

Figure 72: Underwent bone marrow biopsy/aspiration - by leukaemia type

Of those having one of the two procedures, 80% of respondents said they were offered pain relief and 20% said they were not offered any pain relief. There was very little difference of provision of pain relief between the procedures. However, CML respondents were less likely to report being offered pain relief compared to the other leukaemia types – 65% having a bone marrow aspiration and 75% having a bone marrow biopsy were offered pain relief.

62% of respondents experienced moderate or severe pain during the procedure, just 11% of people said that there was no pain. There was little difference between the two procedures.

"the bone marrow test was of the worst experiences I have ever been through, it was like having a six inch nail hammered into your bones." - [AML patient, 55-64]

Although we cannot say that all patients offered pain relief accepted it; the respondents who were offered pain relief were less likely to report experiencing severe pain than those who were not, and instead were more likely to report moderate or mild pain.

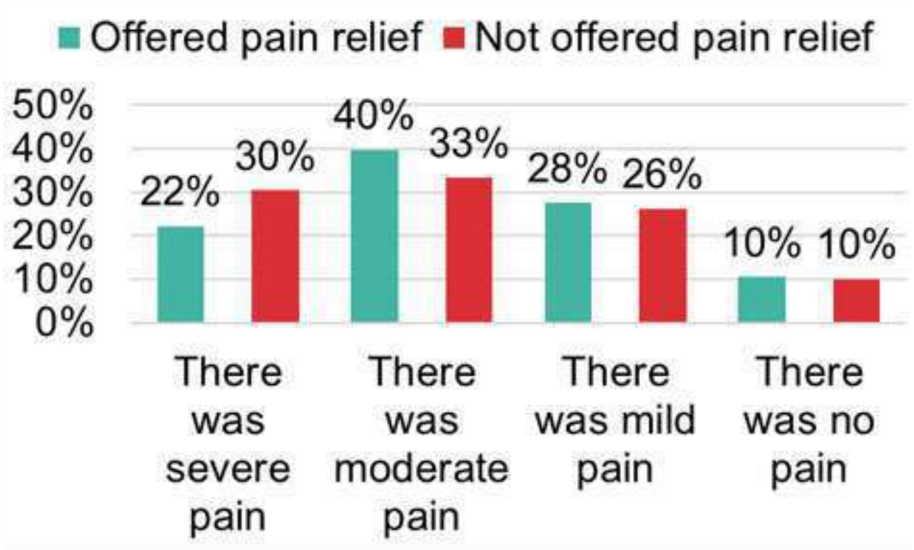

Figure 73: Severity of pain - by provision of pain relief

3.9.4 Respondents undergoing tests for chromosome abnormalities

We asked respondents if they had undergone tests for chromosome abnormalities as part of their monitoring; 27% said "Yes" and 73% said "No". AML and CML respondents were more likely to say they had these tests.

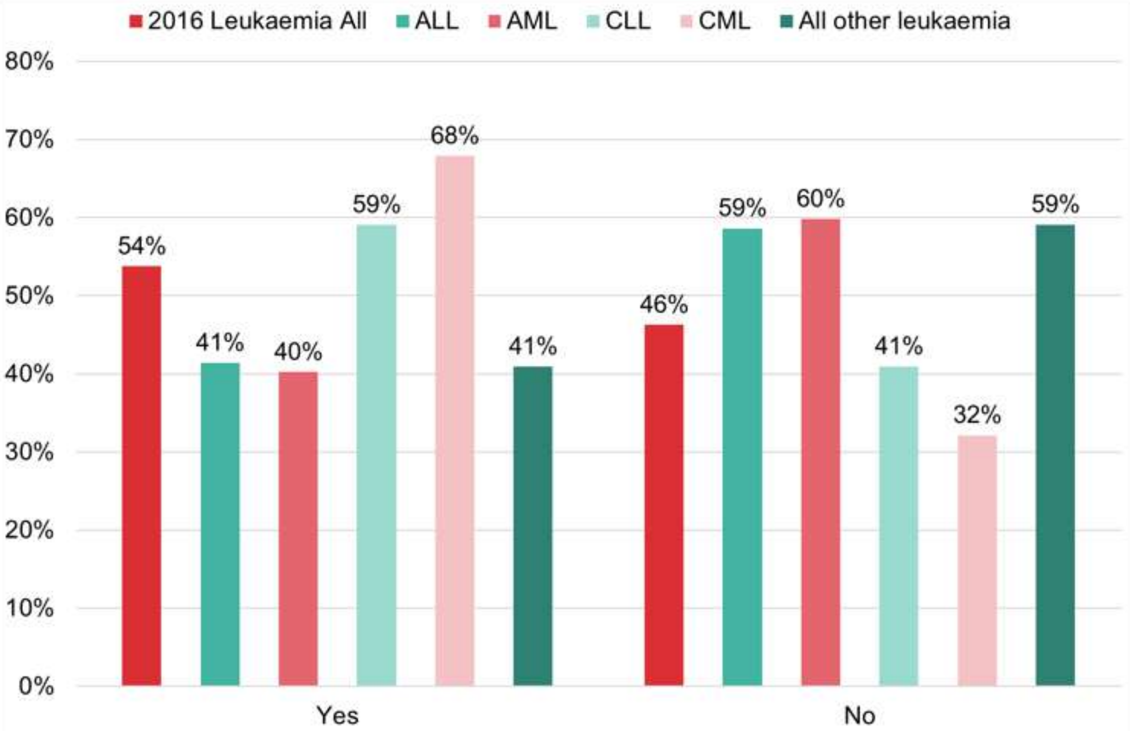

Figure 74: Undergone tests for chromosome abnormalities - by leukaemia type

Of those who said they had undergone these types of tests 11% of respondents were not given full information or explanation of their results.

3.10 Views on potential new treatments

In this section of the survey we wanted to find out respondents' views and preferences for different aspects of potential new treatments

3.10.1 Treatment free periods

Whilst the overall results suggest quite an even split between those who would consider it positive to have a treatment-free period and those who would not; the results by leukaemia type show some pronounced differences in opinion. Respondents with a chronic leukaemia were more positive about this idea then acute respondents: 59% of CLL respondents and 68% of CML respondents agreed.

The full breakdown can be seen below:

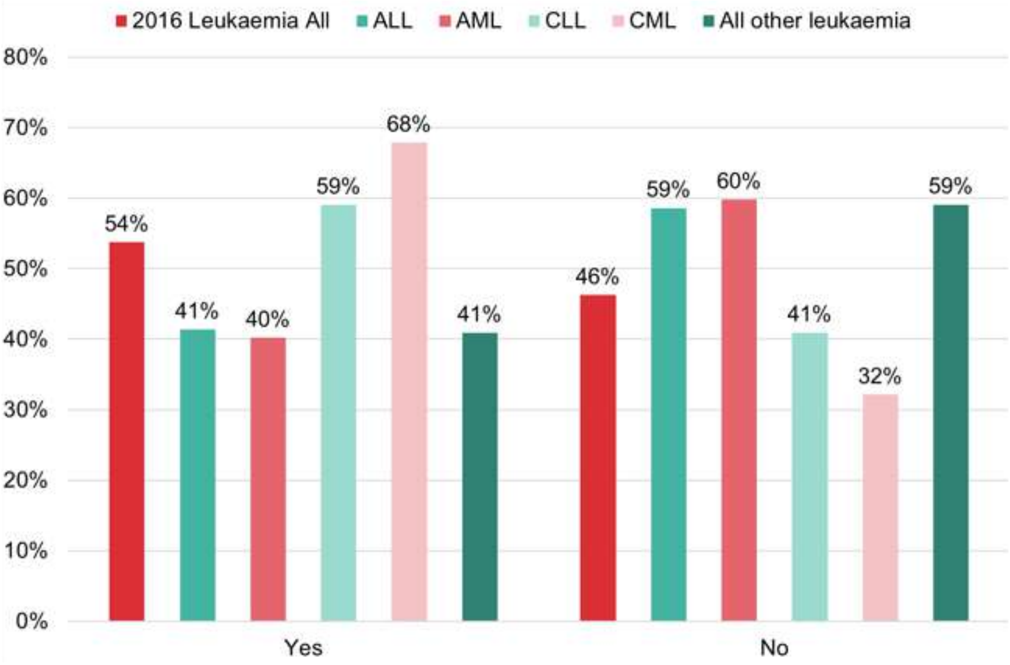

Figure 75: Agreement that a treatment free period would be a benefit - by leukaemia type

3.10.2 Place of treatment

Overall, the majority of respondents (64%) expressed that they would prefer to receive treatment as an outpatient. However, there were differences between the leukaemia types, as the chart below shows:

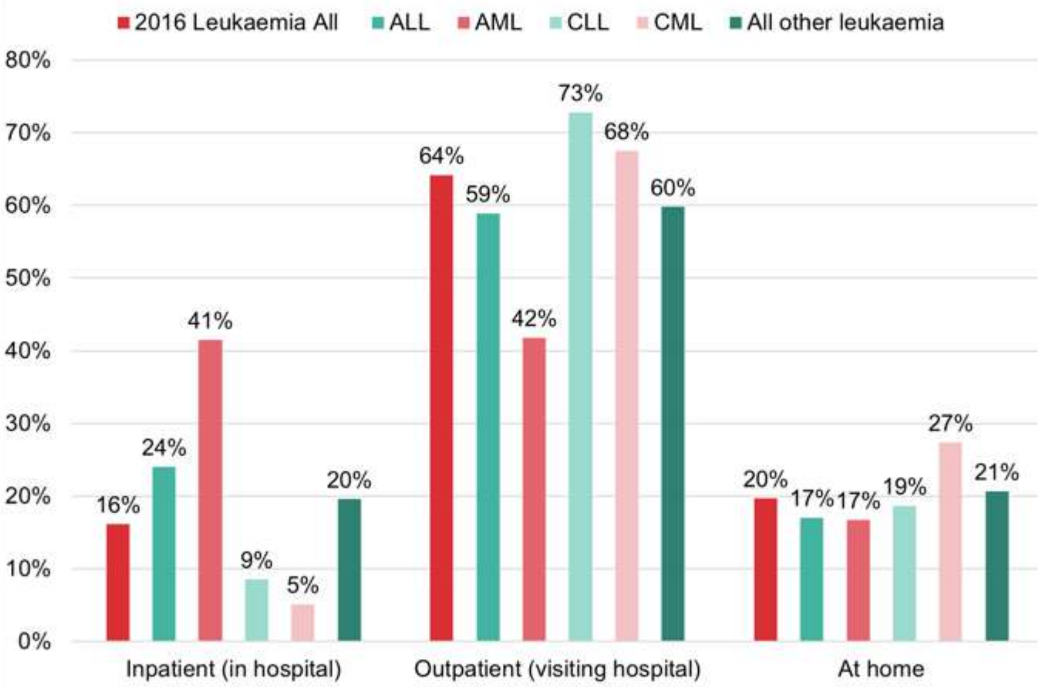

Figure 76: Preference of where to receive treatment - by leukaemia type

3.10.3 Treatment methods

We asked respondents to tell us which method of treatment delivery they would prefer – multiple selections could be made.

Overall, over half (53%) of all respondents preferred an oral tablet and over a third (37%) said through an intravenous infusion. However, there are some wide variation in preferences of treatment delivery between leukaemia types.

One clear difference is within CML, where a large proportion of patients would prefer an oral tablet, but not consider the other options. This possibly reflects current treatment, where an oral tablet is successful with current therapies, and likely to result in normal life expectancy.

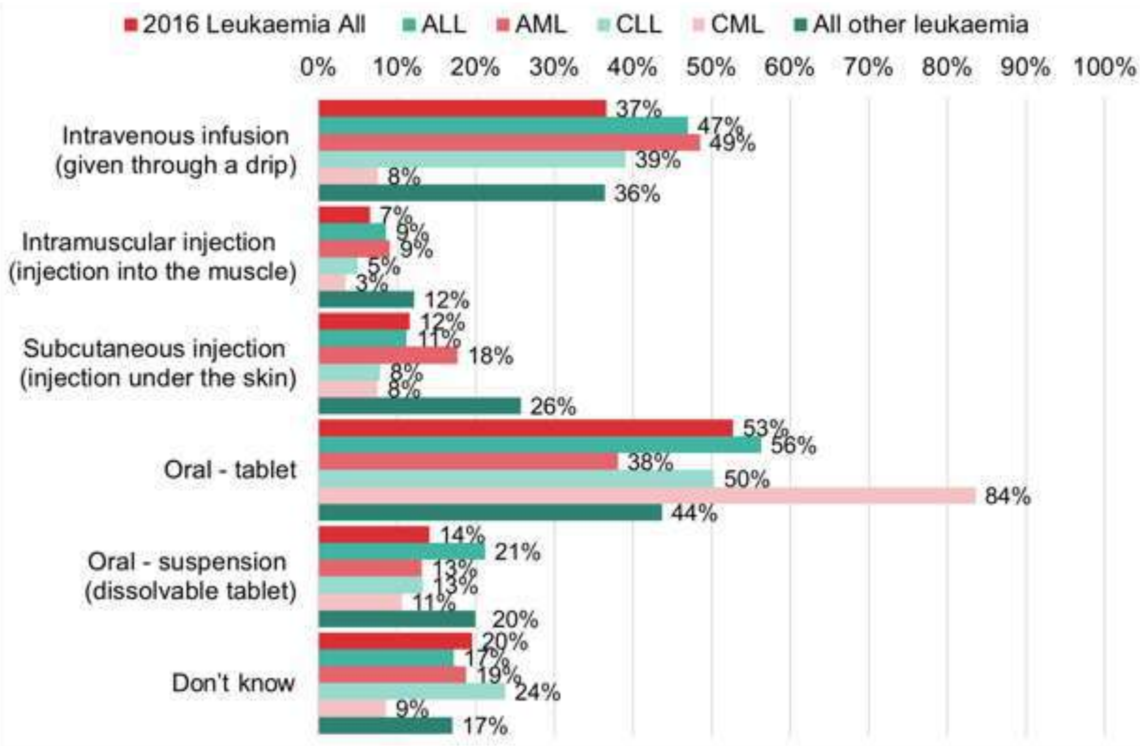

Figure 77: Preference of treatment delivery - by leukaemia type

Treatment method preferences - age breakdown

ALL – Very little variation in preference between < 65 and ≥ 65. <65 more likely to consider and oral suspension (21%, compared to 16%)

AML – < 65 patients were more interested in IV (55%, compared to 39%) and oral tablet treatments (44%, compared to 30%). ≥ 65 patients were more interested in subcutaneous injections (22%, compared to 15%)

CLL – Similar pattern of treatment preferences (IV and Oral tablet most popular) however for nearly all answer options < 65 patients had the higher percentage choosing

CML – Oral tablet was the most frequently selected option by far (86%< 65, and 79%. ≥ 65). ≥ 65 patients were slightly more likely to prefer an injection

Treatment method preferences - gender breakdown

ALL – Females were more likely to say they would prefer IV (53%, compared to 41%) and less likely to say they didn’t know what they would prefer (10%, compared to 24%)

AML – Females were more likely to say they would prefer IV (51%, compared to 46%) but less likely to prefer all the other treatment options and less likely to say they didn’t know what they would prefer (13%, compared to 24%)

CLL – Females were less likely to select any of the treatment options offered, and more likely to say they didn’t know what they would prefer (28%, compared to 21%)

CML – Oral tablet was the most frequently selected option by far (83% female, 84% male). Females were more likely to say they would prefer an oral suspension (14%, compared to 7%)

3.10.4 Additional side effects vs more effective treatment

When asked if they would be willing to experience more side effects for a more effective treatment overall 72% said that yes, they would. There is not much difference between leukaemia types, except for CML respondents; in this group, only 45% would be willing to experience additional side effects. Again, the difference in CML patients may be due to the success of current treatment, and a view that there is not a need for more effective treatment and exposure to more side effects.

3.10.5 Choice of different treatment options

Overall 79% of respondents said they would like a choice of different treatment options. Once again CML had the lowest percentage of respondents, 66% wanted a choice compared to 75% ALL/All other leukaemias, 81% AML and 83% CLL.

3.10.6 Important features of new treatments

We asked respondents to tell us what they considered to be important features of a new treatment – multiple selections could be made.

By far the most selected option was improved/longer survival (79%), followed by improved quality of life (69%). Just under a third (30%) of respondents selected certainty of available treatment data/results which indicates a willingness to take risks, and shows less interest in the certainty of results of new treatments. The full list can be seen below:

o	Improved/longer survival	79%
o	Improved quality of life	69%
o	Bring about a remission/response	57%
o	Tolerable side effects	55%
o	Improved blood counts/rest results	49%
o	Reduced impact or carer/family members	35%
o	Certainty of available treatment data/results	30%

In addition, there were differences between the leukaemia types:

- Acute patients were more likely to select improved/longer survival
- Acute patients were more likely to select bring about a remission/response
- ALL patients were more likely to select improved quality of life
- ALL and CML were more likely to select tolerable side effects
- Acute patients were more likely to select reduced impact on carer/family members

3.10.7 Treatment options available on the NHS

We asked respondents if they thought there are enough treatment options currently available on the NHS, 62% said yes there are and 38% said no.

There is a significant difference between the two cohorts, 73% from Arm 1 thought there were enough treatment options available on the NHS compared to just 41% from Arm 2. It is likely that respondents more engaged with charities are more likely to be informed about treatments that aren't available on, or funded by the NHS.

3.10.8 Treatments leading to stem cell transplant

Finally, we asked respondents if they thought it would be a positive if undergoing a treatment would subsequently enable them to have a stem cell transplant. The majority of people, (82%) said that yes, they would consider it a positive. The exception is CML patients, where only 61% felt this would be a positive aspect to a treatment. This response is possibly due to the risk involved with a transplant, when there are already effective treatments available for this type of leukaemia.

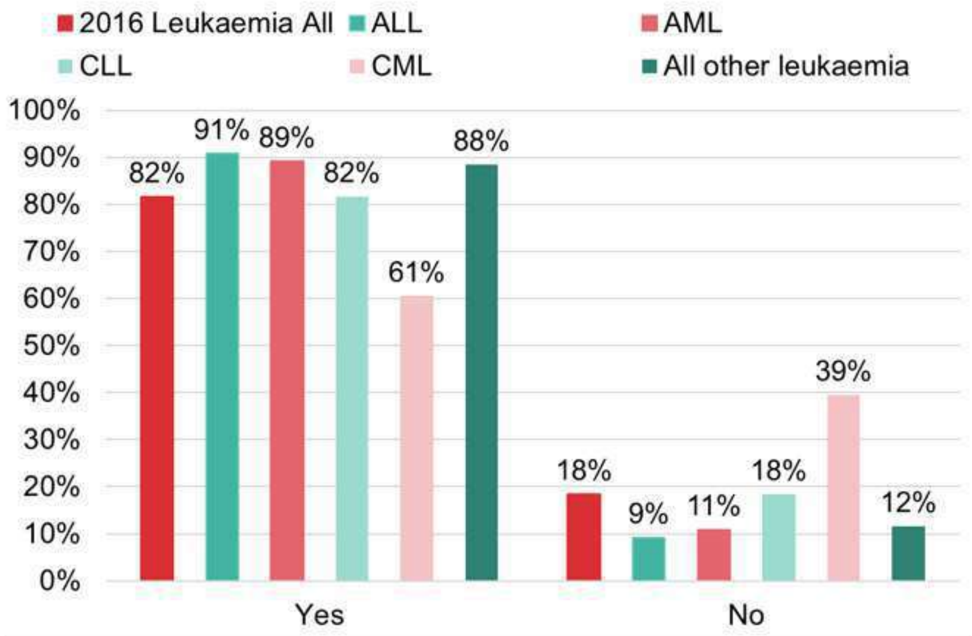

Figure 78: Agreement that treatment leading to a stem cell transplant would be a positive - by leukaemia type

Appendix 1 – Additional breakdown data

a. Anonymous survey data compared to CPES data responses

It should be noted that Arm 2 contained a smaller percentage of AML patients, (12%, compared to 22% Arm 1) and a much larger percentage of CML patients, (28%, compared to 8% in Arm 1). This is likely to be a contributing factor to some of the differences in the results.

In more detail, those responding to the survey from Arm 2 are:

More likely to experience the following symptoms (question 1):
- o **Fatigue** 60%, compared to 55% overall – 53% Arm 1
- o **Sleeping problems** 24%, compared to 19% overall – 17% Arm 1
- o **Headaches** 14%, compared to 10% overall – 8% Arm 1
- o **Frequent and repeated infections** 23%, compared to 17% Arm 1
- o **Fever/night sweats** 34%, compared to 28% overall – 25% Arm 1
- o **Pain in bones/joints** 23%, compared to 18% overall – 16% Arm 1
- o **Swollen stomach or abdominal discomfort** 15%, compared to 11% overall – 9% Arm 1

Less likely to say that their GP had a complete understanding of blood cancers (question 2), (31%, compared to 44% overall – 53% Arm 1); and far more likely to say their GP did not seem to know about blood cancers (27%, compared to 19% overall – 15% Arm 1)

Of those who experienced symptoms and went to their GP (question 4) - Less likely to see their GP within a month of experiencing symptoms (question 4), (36%, compared to 42% overall – 45% Arm 1)

More likely not to think anything was wrong/be asymptomatic (question 4) (21%, compared to – 15% Arm 1)

Less likely to see their GP once before being told they needed to go to hospital (question 5), (35%, compared to 40% overall – 43% Arm 1)

More likely to say they had not heard about leukaemia before they were diagnosed (question 10), (21%, compared to 15% Arm 1)

Less likely to say that they completely understood the explanation of what was wrong with them (question 11), (38%, compared to 50% overall – 56% Arm 1) more likely to say they did not understand the explanation (11%, compared to 6% overall – 4% Arm 1)

Less likely to be told their prognosis or survival chances were good (question 12), (57%, compared to – 62% Arm 1)

More likely not to be told anything about their prognosis or survival chances (question 12), (23%, compared to – 18% Arm 1)

Less likely to have a spouse or partner with them when they were told they had cancer (question 13), (41%, compared to 46% overall – 49% Arm 1) and more likely to be with a parent or guardian (8%, compared to 3% Arm 1), or be on their own (43%, compared to 38% Arm 1)

Less likely to say that they fully understood the reasons for being placed on ‘watch and wait’ (question 15), (50%, compared to 59% overall – 64% Arm 1)

More likely to say that they were very concerned/worried about being placed on ‘watch and wait’ (question 16), (26%, compared to 12% overall – 4% Arm 1) and less likely to say they did not have any concerns or worries (31%, compared to 46% overall – 55% Arm 1)

Less likely to say that they were given understandable written information about ‘watch and wait’ (question 17), (48%, compared to 56% overall – 62% Arm 1) and more likely to say they found the information given difficult to understand (11%, compared to 6% Arm 1), or were not given written information (37%, compared to 33% overall – 31% Arm 1)

Less likely to say that they did not need written information about ‘watch and wait’ (question 17), (6%, compared to 13% Arm 1)

More likely to say that treatment hasn’t started yet (question 18), (56%, compared to 25% overall – 7% Arm 1)

Less likely to say that they were definitely involved as much as they wanted to be in decisions about treatment and care (question 19), (59%, compared to 72% overall – 79% Arm 1) and more likely to say they were not involved as much as they wanted to be (11%, compared to 6% overall – 3% Arm 1)

Less likely to have started treatment following diagnosis within a month (question 20), (5%, compared to 11% Arm 1), and more likely to still be on ‘watch and wait’ (27%, compared to 11% overall – 3% Arm 1)

Less likely to be offered a choice of treatment options (question 21), (28%, compared to 33% Arm 1)

Less likely to say their symptoms have significantly improved following their most recent/current treatment (question 23), (31%, compared to 37% Arm 1)

More likely to experience the following side effects (question 24):
- **Muscle or joint pains** 35%, compared to 30% overall – 27% Arm 1
- **Bone and joint pain** 28%, compared to 24% Arm 1
- **Loss of concentration or memory** 27%, compared to 22% Arm 1

Less likely to experience the following side effects (question 24):
- **Fatigue** 56%, compared to 63% Arm 1
- **Constipation** 15%, compared to 20% overall – 23% Arm 1
- **Bruising** 13%, compared to 18% overall – 21% Arm 1
- **Unexplained weight loss (or loss of appetite)** 12%, compared to 17% overall – 20% Arm 1
- **No side effects** 3%, compared to 8% overall – 10% Arm1
- **Another side effect not listed** 10%, compared to 16% Arm 1

More likely to say the side effects of their most recent or current treatment had a large impact (question 26), (43%, compared to 34% overall – 31% Arm 1) and less likely to say side effects were barely noticeable (11%, compared to 18% overall – 21% Arm 1)

Less likely join a clinical trial (question 27), (38%, compared to 43% Arm 1)

Less likely to say they joined the clinical trial to help further research (question 28), (58%, compared to 63% Arm 1)

Less likely to say they did not join the clinical trial because they were not eligible/rejected (question 29), (25%, compared to 30% Arm 1)

More likely to experience the following symptoms since diagnosis (question 30):

- **Fatigue** 74%, compared to 68% overall – 64% Arm 1
- **Sleeping problems** 43%, compared to 36% overall – 32% Arm 1
- **Headaches** 22%, compared to 17% overall – 15% Arm 1
- **Frequent and repeated infections** 30%, compared to 25% Arm 1
- **Fever/night sweats** 32%, compared to 26% Arm 1
- **Pain in bones/joints** 42%, compared to 30% overall – 24% Arm 1
- **Swollen stomach or abdominal discomfort** 21%, compared to 15% Arm 1
- **Memory/loss of concentration** 36%, compared to 28% overall – 23% Arm 1
- **Palpitations/heart irregularities** 16%, compared to 10% Arm 1
- **Muscle pain** 30%, compared to 23% overall – 20% Arm 1
- **Back/lowerback pain** 25%, compared to 20% overall – 18% Arm 1

Less likely experience the following symptoms since diagnosis (question 30):

- **Unexplained weight loss (or loss of appetite)** 16%, compared to 22% overall – 26% Arm 1

More likely to experience regular pain as a direct result of their condition (question 31), (21%, compared to 16% overall – 14% Arm 1) and less likely to experience no pain (38%, compared to 49% overall – 54% Arm 1)

More likely to have had to reduce their working hours or time in education as a result of their diagnosis (question 33), (29%, compared to 23% Arm 1)

More likely to be in work or education before their diagnosis, (question 33), (71%, compared to 58% overall – 51% Arm 1)

More likely to experience a negative financial impact as a result of their cancer (question 33), (47%, compared to 40% overall – 37% Arm 1) and less likely to experience no impact on spending/income (47%, compared to 54% overall – 58% Arm 1)

More likely to have felt depressed or anxious more often since their diagnosis (question 38), (53%, compared to 42% overall – 36% Arm 1) and less likely to experience no change in their emotional well-being (25%, compared to 36% overall – 42% Arm 1)

Less likely to say that they were given information about support or self-help groups (question 39), (62%, compared to 78% overall – 86% Arm 1) and more likely to say they were not given information but would have liked it (38%, compared to 22% overall – 14% Arm 1)

Less likely to say that information about support or self-help groups wasn't necessary (question 39), (10%, compared to 16% Arm 1)

More likely to say that they were given just written information about support or self-help groups (question 40), (31%, compared to 21% overall – 17% Arm 1) and less likely to say they were given both verbal and written information (56%, compared to 66% overall – 71% Arm 1)

More likely to be given information about support or self-help groups at diagnosis (question 40), (46%, compared to 38% overall – 34% Arm 1) and less likely before starting treatment (25%, compared to 36% overall – 41% Arm 1), during treatment (26%, compared to 32% overall – 34% Arm 1) or at all time points (17%, compared to 22% Arm 1)

Less likely to say they understood all information they were given about support or self-help groups (question 42), (61%, compared to 66% overall – 68% Arm 1 and more likely just to understand some of it (36%, compared to 31% overall – 29% Arm 1)

Less likely to be told by their diagnosing health professional to find further information by coming back to the hospital (question 43), (21%, compared to 28% overall – 32% Arm 1) and more likely to have been recommended Leukaemia CARE (16%, compared to 10% overall – 8% Arm 1) or not to have been recommended anything (38%, compared to 30% overall – 25% Arm 1)

More likely to have been told by their diagnosing health professional not to look at the internet and to not trust online information (question 44), (16%, compared to 10% Arm 1) but also been told to look on internet at trusted websites (25%, compared to 19% Arm 1) and less likely not to have anything said to them about the internet (59%, compared to 67% overall – 72% Arm 1)

More likely to have used the internet and found further, useful information (question 45), (68%, compared to 51% overall – 41% Arm 1), and less likely not have used the internet to find further information (20%, compared to 39% overall – 49% Arm 1)

Less likely to have got support from their hospitals own services (question 46), (28%, compared to 36% overall – 40% Arm 1), say they did not need support (6%, compared to 13% overall – 17% Arm 1) or not have received any support (13%, compared to 18% Arm 1) and more likely to have received support from Leukaemia CARE (29%, compared to 13% overall – 5% Arm 1), Bloodwise (19%, compared to 10% overall – 5% Arm 1), CLL Support Association (24%, compared to 11% overall – 4% Arm 1) and CML Support Association (12%, compared to 5% overall – 1% Arm 1)

Less likely to say the information they were given was excellent (question 47), (24%, compared to 29% Arm 1)

Less likely to have been given access to a CNS (question 49), (32%, compared to 38% overall – 41% Arm 1) more likely not to have been offered additional support (45%, compared to 41% overall – 38% Arm 1)

More likely to have accessed additional support but not felt better/more positive as a result (question 50), (15%, compared to 9% Arm 1) and less likely to say they did not access the support (26%, compared to 32% Arm 1)

Less likely to think their GP was given enough information about their condition and hospital treatment (question 52), (80%, compared to 89% overall – 93% Arm 1) and more likely to think this was not the case (20%, compared to 11% overall – 7% Arm 1)

Less likely to think GPs and nurse at their general practice definitely did everything to support them during their treatment (question 53), (33%, compared to 45% overall – 51% Arm 1) and more likely to think they could have done more (17%, compared to 8% Arm 1), or that their GP practice was of no help (24%, compared to 19% overall – 17% Arm 1)

Less likely to say their GP had access to their hospital records and understood what treatment they had received (question 54), (77%, compared to 84% overall – 87% Arm 1) and more likely to say they were signposted to other sources of information and support (9%, compared to 4% Arm 1)

Time in remission or response (question 56), less likely to say:

- **Treatment or remission ongoing** 22%, compared to 28% Arm 1
- **6-12 months** 5%, compared to 12% Arm 1
- **1-2 years** 8%, compared to 20% overall – 26% Arm 1

o **2-3 years** 5%, compared to 8% overall – 10% Arm 1

Time in remission or response (question 56), more likely to say:
o **5-10 years** 11%, compared to 5% Arm 1
o **10 years or more** 12%, compared to 6% overall – 3% Arm 1
o **Not applicable** 21%, compared to 10% overall – 4% Arm 1

Less likely to have had a relapse (question 57), (21%, compared to 26% overall – 27% Arm 1) Less likely to have had an allogenic stem cell transplant (question 59), (10%, compared to 15% overall – 17% Arm 1), and more likely not to have had a stem cell transplant as part of their treatment (85%, compared to 79% Arm 1)

Total time since first started treatment (question 60), more likely to say:
o **1-3 years** 23%, compared to 46% overall – 57% Arm 1
o **5-10 years** 21%, compared to 15% overall – 13% Arm 1
o **10 years or more** 24%, compared to 13% overall – 9% Arm 1

Less likely to be tested or monitored every month (question 62), (14%, compared to 25% overall – 32% Arm 1) or every 3 months (44%, compared to 49% Arm 1) and more likely to be tested every 6 months, (24%, compared to 15% overall – 11% Arm 1) or once a year, (12%, compared to 5% overall – 1% Arm 1)

Less likely to be given a complete and understandable explanation of their regular testing or monitoring (question 63), (55%, compared to 74% overall – 83% Arm 1), and more likely to have to ask to get an understandable explanation (17%, compared to 11% overall – 8% Arm 1); to only understand part of the explanation they were given, (21%, compared to 13% overall – 9% Arm 1) or not be given an explanation even though they would have liked one, (7%, compared to 1% Arm 1)

Less likely to be given a copy of their regular testing or monitoring results to take away, without having to ask, (question 64), (31%, compared to 43% overall – 51% Arm 1), and more likely to have to ask for a copy of the results (24%, compared to 19% overall – 16% Arm 1); or not be given a copy of their results even though they would have liked this, (44%, compared to 38% overall – 33% Arm 1)

Less likely to have had a bone marrow biopsy (question 65), (46%, compared to 64% overall – 74% Arm 1) and more likely to have had a bone marrow aspiration (20%, compared to 15% overall – 12% Arm 1) or not to have had either of these procedures, (34%, compared to 22% overall – 15% Arm 1)

More likely to have experienced severe pain during their bone marrow procedure (question 67), (32%, compared to 24% overall – 20% Arm 1) and less likely say there was mild pain (21%, compared to 27% overall – 30% Arm 1) or no pain (7%, compared to 12% Arm 1)

Less likely to have a negative result to a mutation test (question 69), (27%, compared to 32% overall – 30% Arm 1) and more likely not to have been told or informed of their test results (15%, compared to 9% overall – 4% Arm 1)

More likely to have consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether (question 70), (67%, compared to 54% overall – 48% Arm 1)

Less likely to prefer to be treated as an outpatient (question 71), (57%, compared to 64% overall

– 68% Arm 1), and more likely to want to be treated at home (28%, compared to 20% overall – 15% Arm 1)

More likely to prefer their treatment to be delivered as an oral tablet (question 72), (56%, compared to 51% Arm 1) and less likely to prefer; intravenous infusion (25%, compared to 43% overall – 37% Arm 1) and subcutaneous injection (8%, compared to 13% Arm 1)

More likely to like a choice of different treatment options (question 74), (86%, compared to 79% overall – 74% Arm 1)

More likely to consider important features of a new treatment to be (question 75): bring about a remission (61%, compared to 54% Arm 1), improved quality of life (75%, compared to 69% overall – 66% Arm 1), tolerable side effects (64%, compared to 55% overall – 51% Arm 1) and certainty of available treatment data/results (35%, compared to 30% overall – 27% Arm 1)

Less likely to think there are enough treatment options currently available on the NHS (question 76), (41%, compared to 62% overall – 73% Arm 1)

Less likely to consider it positive if a treatment would subsequently enable a stem cell transplant (question 77), (77%, compared to 82% overall – 84% Arm 1)

The age group of the Arm 2 respondents is slightly younger, with more respondents in the 45-54 age bracket (19%, compared to 13% overall – 10% Arm 1) and 55-64 (31%, compared to 25% overall – 22% Arm 1) and fewer in the 65-74 (30%, compared to 36% Arm 1) and 75-84 (7%, compared to 16% overall – 21% Arm 1)

Arm 2 respondents contained fewer male respondents (45%, compared to 57 overall – 63% Arm1) and more females (55%, compared to 43% overall – 37% Arm 1)

For more information on the report, go to:
www.leukaemiacare.org.uk/living-with-leukaemia

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