Leukaemia Care
YOUR Blood Cancer Charity

Leukaemia Care
Living with Leukaemia

2018 Report

www.leukaemiacare.org.uk

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:

1. **Acute myeloid leukaemia (AML)** – Rapidly developing, affects myeloid cells (granulocytes)
2. **Chronic myeloid leukaemia (CML)** – Slowly developing, affects myeloid cells (granulocytes)
3. **Acute lymphoblastic leukaemia (ALL)** – Rapidly developing, affects lymphocytes
4. **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. In 2016 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.

Following the success of the 2016 Living with Leukaemia Survey, Leukaemia Care decided to re-run the survey in 2017. The aim was to measure and track annual comparisons and explore certain topics and areas in more detail.

The 2017 survey was sent to 1680 leukaemia patients identified using the National Cancer Patient Experience 2016 Survey, and who had consented to be contacted again. There were 1205 responses received, resulting in a response rate of 73%.

Leukaemia Care also sent the survey to 1173 leukaemia patients identified from their database, where they had given consent to be contacted and just a postal address. There were 557 responses received, resulting in a response rate of 49%. Of these respondents, 508 identified themselves as leukaemia patients, and the rest were other blood cancer patients.
In addition, an anonymous online survey of the wider blood cancer community was run, and publicised by blood cancer charities through various online and print channels. 1122 people completed the online questionnaire, of which 616 identified themselves as leukaemia patients, and the rest were other blood cancer patients.

The main profile of the leukaemia respondents was as follows:

- 52% came from CPES, 22% came from Leukaemia Care database, and 26% were from the anonymous cohort

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

- 55% were male, 45% 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

Once again, the results from the survey have created a robust dataset. The data continues to reveal 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. These areas are listed below.

Awareness of leukaemia as an aid to earlier diagnosis

It is widely acknowledged that an early diagnosis can have a significant impact on the outcome for cancer patients, and this is certainly true for leukaemia. Patients diagnosed via an emergency route have a lower 1-month and 12-month survival, than those diagnosed by other routes, and this is true across all leukaemia types.

The difficulty faced, is that while there are numerous signs and symptoms associated with leukaemia, they are notoriously vague, non-specific, and can be associated with other health problems. Although a doctor may suspect a patient has leukaemia based on signs and symptoms, it can only be diagnosed by laboratory tests.

Following the results of our 2016 survey we recommended that there needed 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)*. Leukaemia Care launched the ‘Spot Leukaemia’ campaign with the aim of raising awareness of what leukaemia is, the symptoms to spot and who can be affected by leukaemia. We also host an eLearning tool in collaboration with the Royal College of General Practitioners (RCGP) to support GPs and equip them with the knowledge to spot the signs and symptoms of blood cancer earlier, as well as in person training events around the country.

The results of the 2017 survey show that although most patients (85%) said they experienced symptoms before their diagnosis, very few people expected (4%) or suspected (17%) that they may have cancer. 45% of acute leukaemia patients and 73% of chronic leukaemia patients said they waited over a month before going to see their GP. On average, 15% of leukaemia patients said they visited their GP more than three times before they were referred to hospital. These results show little change and no improvement since the 2016 survey or by year of diagnosis. In addition, less than half (48%) of respondents felt their GP had a complete understanding of blood cancers, and this has shown no significant improvement over time (by respondents’ year of diagnosis).

Recommendation 1: Work and campaigning needs to continue in order to improve 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).

Financial impact of living with leukaemia

One of the most important areas for leukaemia patients is the impact of cancer on their finances. On average, 43% of people reported experiencing a negative impact on their finances, and this ranges between 36% and 56% across the different leukaemia types.

64% of patients reporting a negative impact on their finances (23% of all respondents) had experienced an increase to their monthly costs.

70% of patients reporting a negative impact on their finances (27% of all respondents) had experienced a reduction to their income.

Despite improvement, only 61% of leukaemia patients from 2016 CPES said that hospital staff gave them information about how to get financial help or benefits they might be entitled to. Considering the number of leukaemia respondents reporting a negative impact (whether permanent or temporary), it is important that they are signposted to places they can find and access help.

Recommendation 2: The support and advice given by hospitals about the financial impact of leukaemia needs to continue to improve, incorporating signposting to organisations who offer specialised financial support.

Emotional impact

In 2016 we highlighted the emotional changes that can be caused by a leukaemia diagnosis. Understandably, patients reporting a negative change in their emotional well-being is an ongoing issue in the 2017 survey. Leukaemia patients will continue to 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.

We have identified that some groups of respondents are more likely to report a negative emotional impact, such as those still on ‘watch and wait’, who have relapsed, or are living with dependent children.

The 2017 survey showed that opportunities to offer emotional support are still being missed. 96% of leukaemia patients wanted information, but of these only 46% were given information on emotional support (59% acute, 39% chronic). In addition, on average only 18% of patients said they were offered counselling or psychotherapy, ranging from 43% 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 3: More importance needs to be placed on the psychological and emotional needs of leukaemia patients. Signposting to appropriate services should be offered to all patients, and should consider those who may be more ‘at risk’ from deterioration to their mental health, e.g. due to personal circumstances or treatment path.

2. Leukaemia type executive summary

The following section looks at each main type of leukaemia and highlights the issues that are markedly prevalent within each.

ALL

Awareness of ALL and route to diagnosis

Early diagnosis is a major factor in the prognosis for people with ALL. However, our results show that there are still barriers causing delays in diagnosis. The lack of awareness of potential ALL symptoms and delay in presentation to a healthcare professional is one such issue, as is the number of people who are initially treated for another condition.

The most common symptoms reported for ALL were:
- **Fatigue** 77%
- **Feeling weak or breathless** 64%
- **Fever / night sweats** 42%
- **Easily bruise or bleed** 41%
- **Unexplained weight loss (or loss of appetite)** 31%

Although 56% of ALL patients waited less than a month from experiencing symptoms to visiting a healthcare professional, around a third (34%) waited between 1- 3 months and 10% said they waited longer than 3 months.

35% of ALL patients were sent by their GP to the hospital on the same day and 22% were seen as an emergency/A&E patient. However, over a quarter (27%) were initially treated by their GP for another condition. The NCIN routes to diagnosis report highlights that 65% of patients with ALL are diagnosed by emergency presentation, which is the highest of any cancer type (all cancer average is 22%).

Recommendation 4: Campaigning needs to continue in order to improve awareness for ALL amongst both the public and healthcare professionals.

Financial impact of ALL

55% of ALL patients reported a negative impact on their financial situation. 70% of these said their monthly costs had increased, and 77% said their income had reduced. This is likely to be influenced by these patients undergoing or having undergone active treatment, and being affected by financial issues such as travel, childcare, and taking time off work for appointments. In addition, 65% of ALL patients who were in employment said they had had to stop working, either permanently or temporarily, as a result of their diagnosis.

Recommendation 5: ALL patients should be made aware of, or signposted to, where they can find out about benefits they may be eligible for, both during and after treatment, and where to find advice on employment e.g. their employee rights and returning to work.

AML

Awareness of AML and route to diagnosis

Early diagnosis is also important for patients with AML, as it accounts for over half of leukaemia related deaths. However, as with ALL, our results show that the same barriers are present: lack of awareness of potential symptoms, delayed presentation to a healthcare professional, and initial treatment for another condition.

The most common symptoms reported for AML were:

- **Fatigue** 69%
- **Feeling weak or breathless** 55%
- **Easily bruise or bleed** 35%
- **Fever / night sweats** 27%
- **Pain in bones / joints** 23%

54% of AML patients waited less than a month from experiencing symptoms to visiting a healthcare professional, but 31% waited between 1- 3 months and 15% said they waited longer than 3 months.

30% of AML patients were sent by their GP to the hospital on the same day and 22% were seen as an emergency/A&E patient. However, 23% were initially treated by their GP for another condition.

Recommendation 6: Campaigning needs to continue in order to improve awareness for AML amongst both the public and healthcare professionals.

Financial impact of AML

56% of AML patients reported a negative impact on their financial situation. 65% of these said their monthly costs had increased, and 78% said their income had reduced. As with ALL, this is likely to be influenced by these patients undergoing or having undergone active treatment, and being affected by financial issues such as travel, childcare, and taking time off work for appointments. 75% of AML patients who were in employment said they had had to stop working, either permanently or temporarily, as a result of their diagnosis.

Recommendation 7: AML patients should be made aware of, or signposted to, where they can find out about benefits they may be eligible for, both during and after treatment, and where to find advice on employment e.g. their employee rights and returning to work.

CLL

'Watch and wait'

78% of CLL respondents who completed the survey reported having been placed on 'watch and wait', and of these over a quarter (28%) are still in active monitoring.

60% of the patients said when they were placed on 'watch and wait', that they fully understood the reasons why. Over half of patients (53%) had concerns or worries: 42% had some concerns and worries, and 11% were very concerned/worried. Whilst the majority of people (84%) wanted written information about 'watch and wait', only around half (56%) were given it and found it easy to understand; 10% said they were given written information, but found it difficult to understand, and the remaining 34% said they were not given written information.

In the 2016 survey we identified that there was a correlation between the amount of written 'watch and wait' information given and how easy it is to understand to how worried a patient feels. The same analysis was run again in 2017 and once again shows the same relationship. Patients not given any information were 3 times more likely to be very concerned/worried about being put on 'watch and wait' than those who were given written information they understood. However, patients who were given information but found it difficult to understand were over 5 times more likely to be very concerned/worried than those who understood the information, and over 1.5 times more likely than those who were not given any information at all. Overall, it was those patients who were given information they found difficult to understand that were most likely to have worries/concerns.

Recommendation 8: CLL patients placed on 'watch and wait' should receive a full and understandable explanation about what this means. Written information should be provided, but should be reviewed to ensure it is clear and understandable, and patients should be given the opportunity (and encouraged) to ask questions about any aspect of 'watch and wait' they do not understand.

Clinical Nurse Specialist

It is widely accepted that the presence of a Clinical Nurse Specialist (CNS) is one of the most powerful positive influences on a cancer patient's experience. Results from the 2016 Cancer Patient Experience Survey reported that 88% of leukaemia patients were given the name of a CNS who would support them through their care. However, the results from our survey indicate that CNS provision is not even across all leukaemia types.

Just 56% of all CLL patients reported that they were given access to a CNS: 61% of those that started treatment straight away, and 54% of those who went onto 'watch and wait'. In addition, only 29% of the CLL respondents who are still on watch and wait said they have access to a CNS. There continues to be a gap, where patients living with a chronic disease and are not in active treatment are missing the opportunity to access a CNS and the support and benefits they offer.

Recommendation 9: The provision of CNSs needs to be increased within CLL, and in particular those still on 'watch and wait'.

CML

Treatment options and involvement

CML patients were least likely to say they were ’definitely involved’ as much as they wanted to be in decisions about their care and treatment (69%), and also least likely to say they were offered a choice of treatment options (28%).

The main way in which CML is treated is by targeted therapy, through the use of tyrosine kinase inhibitors (TKIs). However, there is still the option to give patients choice, as there are five TKIs that are licensed for use in the UK.

The decision about which TKI is suitable for a patient should take into account the treatment’s effectiveness, likely side effects, and how the drug is taken. Side effects vary between TKIs and are likely to be an important factor for a patient, so should be included in treatment discussions. It could also be considered/discussed if the patient would like to ultimately try and achieve treatment-free remission, as there is research to suggest that the use of certain TKIs can be beneficial to this.

Recommendation 10: All clinically appropriate treatment options should be discussed with patients, so that they feel there is an informed choice.

Clinical Nurse Specialist

As with CLL, CML patients were less likely to say that they were given access to a CNS than those patients with an acute leukaemia.

63% of all CML patients reported that they were given access to a CNS compared to 71% of those with an acute leukaemia.

CML patients are most likely to be on continuous treatment for a long period of time, or even indefinitely. Therefore, they may have to manage ongoing long-term side effects and the impact this will have on their work and home life. Even if they are one of a gradually increasing number of patients who will start to try treatment-free remission, they may have to deal with the withdrawal effects from medication, and the emotional impact caused by the worry of disease reoccurrence. Therefore, it is still important that CML patients are given access to a CNS who can support and advise with all of these impacts.

Recommendation 11: The provision of CNSs across CML needs to be increased, to ensure the support of patients living long term with a chronic disease.

3. Background and methodology

3.1 Background and objectives

The Living with Leukaemia Survey 2017 is the second iteration of the survey, which was first undertaken in 2016. This project was designed as a follow up to NHS England's annual Cancer Patient Experience Survey (CPES). It aims to provide further evidence on leukaemia patient experience, with a focus on the varying needs of patients with different forms of leukaemia.

The survey 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 were 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 2016 survey sought to identify areas where leukaemia patients reach out to charities for support, as well as areas that patients need support but had nowhere to reach out to. Through repeating the survey in 2017, the aim was to measure and track annual comparisons and explore certain areas (such as 'watch and wait', and financial impact) in more detail.

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.

3.2 Questionnaire design and development

The original questionnaire was developed and designed over several months in 2016, following detailed discussion between Leukaemia Care and Quality Health. Several changes were made for the 2017 survey; these are detailed in Appendix 1 and summarised below:

- 21 questions removed
- 14 new questions
- 19 amended questions
- 1 section introduction changed

Once the question set was agreed, the questionnaire was tested by seven 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.

3.2.1 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 focus on leukaemia.

The project was carried out using three arms of data collection.

- **Arm 1:** Contacting Leukaemia patients identified using National Cancer Patient Experience 2016 Survey data (CPES) – those who had agreed to be contacted again.
- **Arm 2:** Contacting blood cancer patients from Leukaemia Care's database. Specifically, those who were a leukaemia patient, that Leukaemia Care had consent to contact, and who had a valid postal address, but no email address recorded on the Leukaemia Care database.
- **Arm 3:** An anonymous online survey of the wider blood cancer community – publicised through various online and print channels. This arm also included all blood cancer patients from the Leukaemia Care database that Leukaemia Care had consent to contact, and who had a valid email address.

For Arm 1, the sample was drawn using CPES data from 2016. 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	Promlymphocytic 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 promyeloctic leukaemia (APL)
C925	Haematological	C92	Acute myemonocytic 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	C93	Acute erythroid leukaemia
C944	Haematological	C93	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 samples, Quality Health carried out death checks to ensure that no questionnaire was sent to any person who had since died, and the samples were also checked to ensure that no duplication took place – so no one received more than one questionnaire, this included cross referencing Arms 1 and 2.

At the same time as Arms 1 and 2 were underway, Arm 3 was launched, to target people with any type of blood cancer. 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.

We would also like to thank ACLT, Anthony Nolan, Basil Skyers Myeloma Foundation, Bloodwise, CLIC Sargent, CLL Support Association, Lymphoma Action (formerly the Lymphoma Association), MDS UK, MPN Voice, Myeloma UK, Teenage Cancer Trust 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 and 3 stating they had a confirmed diagnosis of leukaemia but no other blood cancer.

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 referred to these throughout section 3, where this is appropriate and where differences are most pronounced.

3.3 Timescales and fieldwork

The questionnaire was agreed in August 2017. The Arms 1 and 2 send out by post consisted of an initial mailing of the questionnaire 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 and Arm 2 send out took place on 25 September 2017, with reminders following on 16 October and 6 November. The field work closed on 15 December 2016.

Arm 3 was launched at the same time as Phase 1 and was open for completion until 15 December 2016. Where possible, reminder emails were sent on: 13 October 2017, 15 November 2017, and 14 December 2017. The survey was also publicised through Leukaemia Care newsletters sent on 4 October 2017, and 5 December 2017.

3.4 Response rate

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

Arm	**Reponses received**	**Reponse rate**
1	1205	73%
2	557	49%
3	1122	
Total	**2884**	

Arm 1 – Questionnaires were sent to 1680 CPES respondents. 29 were excluded for the following reasons:

Moved / not known at this address	2
Deceased	26
Ineligible	1

Method of questionnaire completion for **Arm 1** was as follows:

Paper questionnaire	1127
Online	76
Telephone completion	2

Arm 2 – Questionnaires were sent to 1173 Leukaemia Care database contacts. 25 were excluded for the following reasons:

Moved / not known at this address	10
Deceased	14
Ineligible	1

Method of questionnaire completion for **Arm 2** was as follows:

Paper questionnaire	524
Online	32
Telephone completion	1

Method of questionnaire completion for **Arm 3** was as follows:

Online questionnaire	1122

All Arms combined saw 2884 completed questionnaires, of which 2329 were leukaemia respondents and 555 had another form of blood cancer.

The breakdown of leukaemia respondents were as follows:

Arm 1 (CPES)	1205
Arm 2 (LC)	508
Arm 3 (anonymous)	616
TOTAL	**2329**

11 respondents stated they had more than one type of leukaemia, therefore the number of respondents by leukaemia type is as follows:

ALL	147
AML	443
CLL	1152
CML	374
All other leukaemia types	224
TOTAL	**2340**

More information on this is detailed in **section 3.1.4**

4. Results of the questionnaire

4.1 Respondent characteristics

4.1.1 Gender

Overall, 55% of respondents were male and 45% were female.

From the CPES cohort, there were slightly more male respondents - 61% male and 39% female. The Leukaemia Care (LC) respondents contained more females - 46% male 54% female. The online cohort had a very even split, 51% male and 49% female. These results suggest that it is females that are more likely to seek support from Leukaemia Care for their condition.

It has been acknowledged that there is often a difference in the reported experience between the genders, with females more likely to report a more negative experience. This is true for our results, with males being more positive on most issues.

There are a few issues where males report some significant, less positive, differences:

- Males were more likely to not join a clinical trial after being offered the option of participating – 11% males, 8% females
- Males were less likely to say they were given information about their blood cancer – males 88%, females 91%
- Males were less likely to be offered additional support in the form of counselling or psychotherapy – males 15%, females 20%
- Males were less likely to say the additional support they accessed helped them feel better – males 57%, females 65%
- Males were more likely to say that they did not access the additional support they were offered – males 32%, females 23%

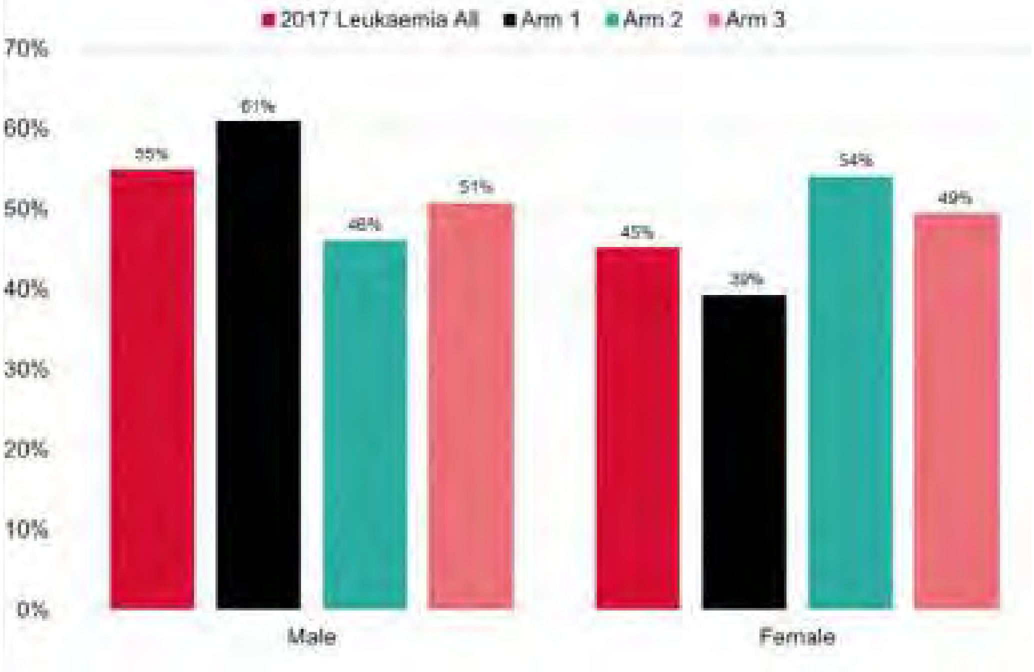


Figure 1: *Distribution of respondents - by gender*

4.1.2 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 and Arm 3. 45-64-year olds were most likely to come through Arm 3 (52%) and the older respondents (65+) were more likely to have been contacted via Arm 1.

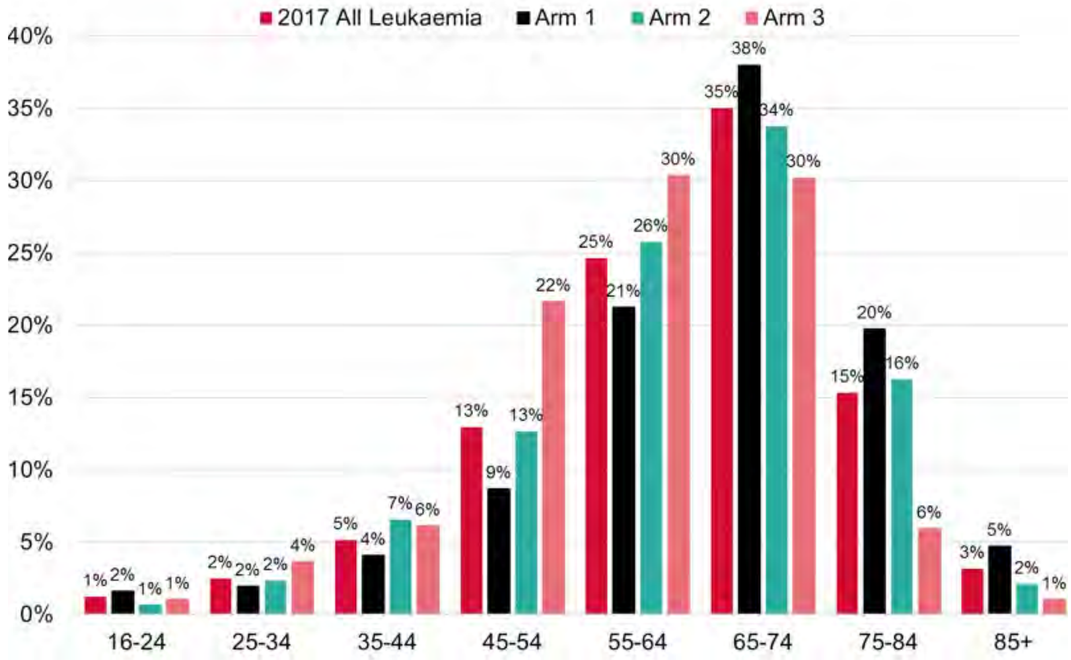
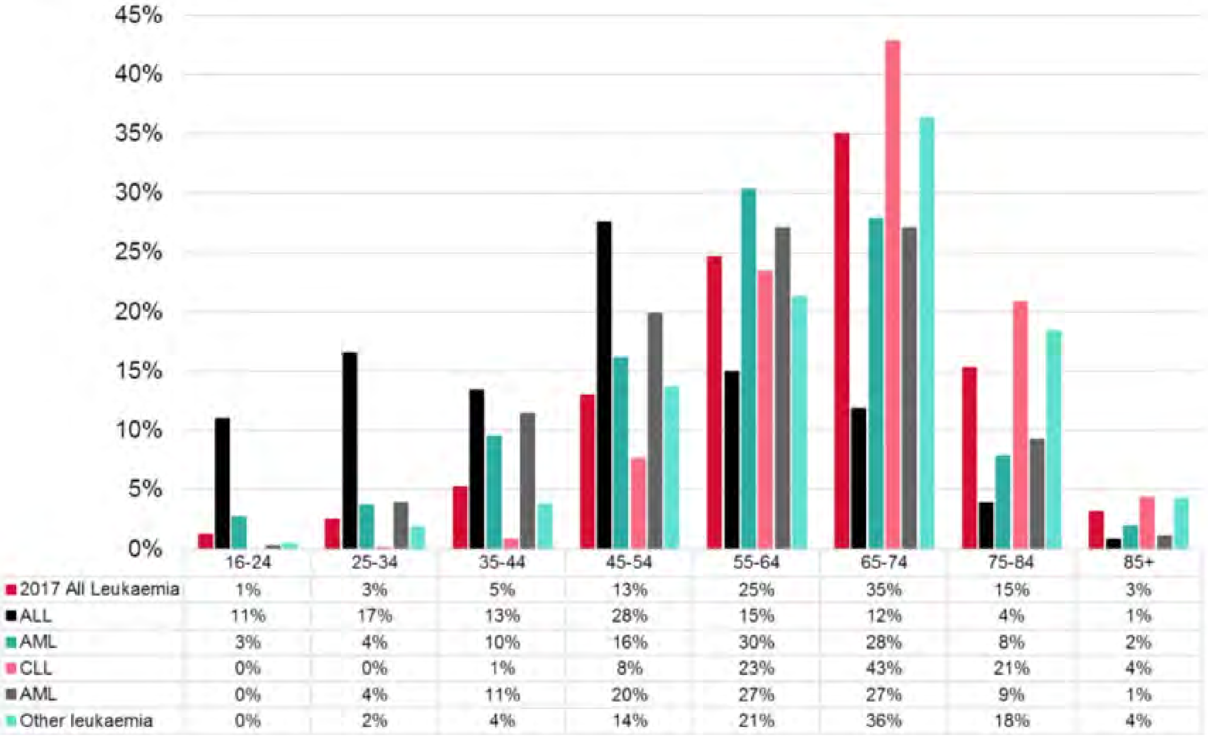


Figure 2: *Distribution of respondents - by age band and patient cohort*

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+
■ 2017 All Leukaemia	1%	3%	5%	13%	25%	35%	15%	3%
■ ALL	11%	17%	13%	28%	15%	12%	4%	1%
■ AML	3%	4%	10%	16%	30%	28%	8%	2%
■ CLL	0%	0%	1%	8%	23%	43%	21%	4%
■ AML	0%	4%	11%	20%	27%	27%	9%	1%
■ Other leukaemia	0%	2%	4%	14%	21%	36%	18%	4%

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

4.1.3 Ethnicity

97% of respondents identified as being White British, 3% as Black and Minority ethnic (BME). There was no significant difference between the three arms of the survey. These demographics are not dissimilar to the National Cancer Patient Experience 2016 Survey, where 95% identified as White British, 5% as BME.

4.1.4 Education

In the 2017 survey we asked respondents to tell us their highest level of qualification. This allowed us to see if there was a relationship between level of education and respondents' responses to several issues such as understanding, emotional well-being and access of support. The chart below illustrates the responses:

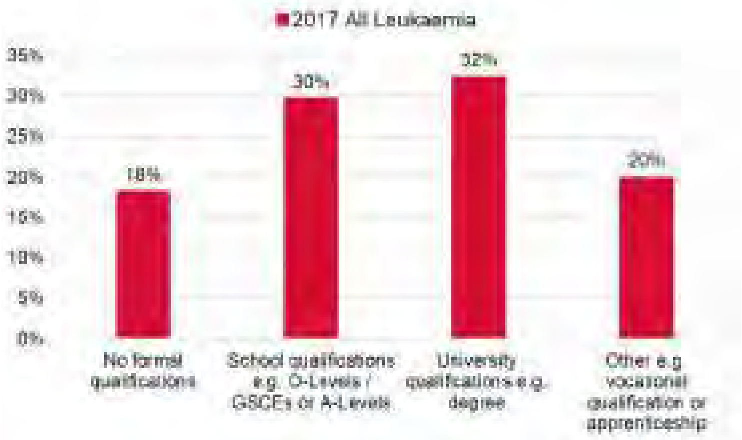


Figure 4: *Education level of respondents*

There were some differences on key areas around understanding, information and emotional change. These include:

- While there were no significant differences between education level and respondent's understanding of the reasons they were placed on 'watch and wait', those with university qualifications were significantly more likely to say they had concerns and worries about being placed on 'watch and wait', compared to those with no qualifications – 60%, compared to 44%.
- Respondents with university qualifications were more likely to say they understood the information they were given about blood cancer - 66% said it was easy to understand and they understood all of it, compared to 52% with vocational qualifications; 46% with school qualifications, and 51% with no qualifications.
- Respondents with university qualifications were more likely to say they felt depressed or anxious more often since their diagnosis – 46% said this, compared to 38% vocational; 43% school, and 33% with no qualifications.
- Respondents with no formal qualifications were significantly less likely to use the Internet to find further information – 61% said they did not use it, compared to 41% vocational; 37% school, and 20% with university qualifications.

4.1.5 Living situation

Another new question for the 2017 survey was around respondents' living situation at diagnosis. This allowed us to analyse the relationship between living situation and several issues such as emotional well-being.

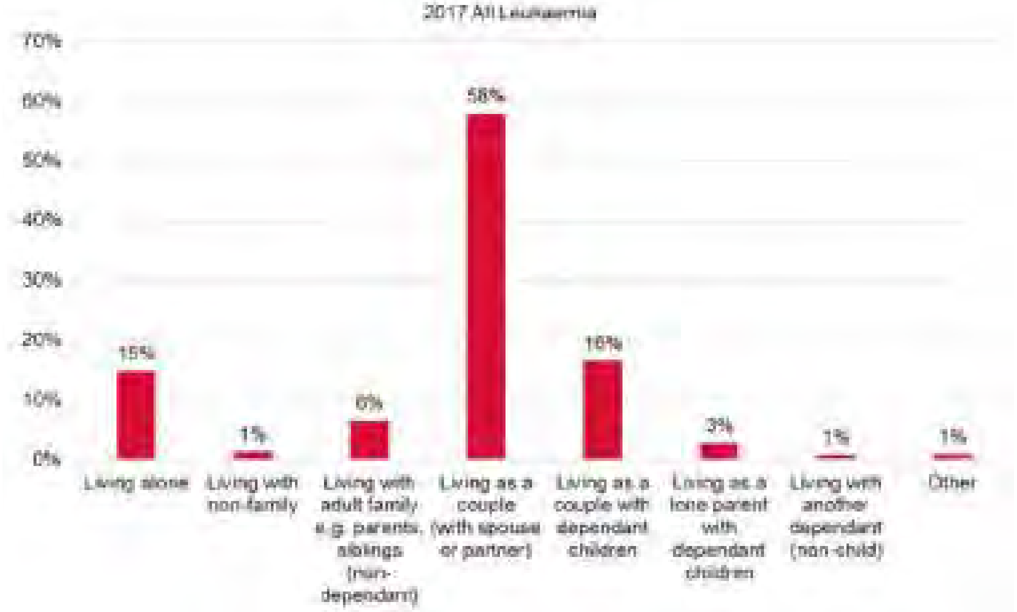


Figure 5: *Living situation at diagnosis*

4.1.6 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 and Arm 3.

Arm 1 contains 1205 leukaemia patients identified using National Cancer Patient Experience 2016 Survey data – the diagnosis is 'physician reported'.

Participants in Arm 2 and Arm 3 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. 11 respondents ticked two types of leukaemia.

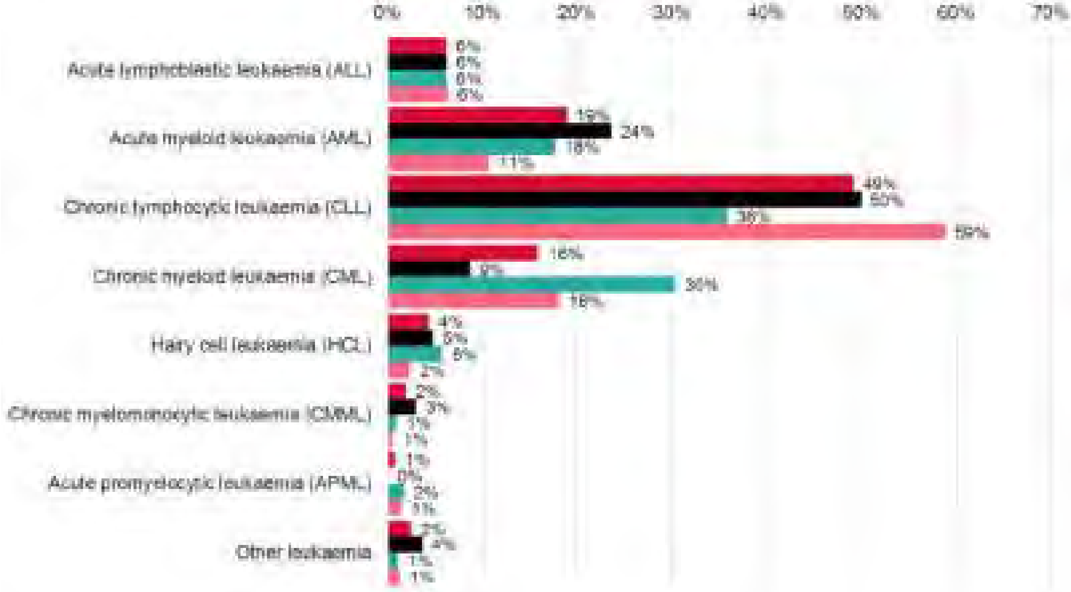


Figure 6: *Distribution - by leukaemia type*

4.1.7 Location

The tables below show the location of respondents.

For Arm 1 we took information from CPES data and grouped respondents into the most recently defined Cancer Alliance/Cancer Vanguard areas.

Cancer Alliance/Cancer Vanguard	
Cheshire and Merseyside	43
East Midlands	106
East of England	149
Humber Coast and Vale	20
Kent and Medway	60
Lancashire and South Cumbria	30
National Cancer Vanguard: Greater Manchester	41
National Cancer Vanguard: North Central and North East London	29
National Cancer Vanguard: North West and South West London	76
North East and Cumbria	99
Peninsula	46
Somerset Wiltshire Avon and Gloucestershire	56
South East London	43
South Yorkshire Bassetlaw North Derbyshire and Hardwick	48
Surrey and Sussex	83
Thames Valley	50
Wessex	59
West Midlands	108
West Yorkshire	46
Not classified	13
Total	**1,205**

Figure 7: *Distribution of respondents from Arm 1 by Strategic Clinical Network*

The table below shows the response from all Arms to the question asking ‘Where do you live?’

Country	
England	2114
Northern Ireland	14
Scotland	94
Wales	55
Non-UK	33
Missing	19
Total	**2,329**

Figure 8: *Distribution of respondents from Arm 2 by country*

4.1.8 Time since diagnosis

Leukaemia Care felt that it was important to ensure that patient experience was measured across the entire patient journey, recognising that there are different needs at different timepoints.

As such, where differences arise, we have reported breakdowns of the data based on year of diagnosis to show how patient experience changes over time.

The chart below shows the breakdown of respondents by their reported year of diagnosis, by leukaemia type.

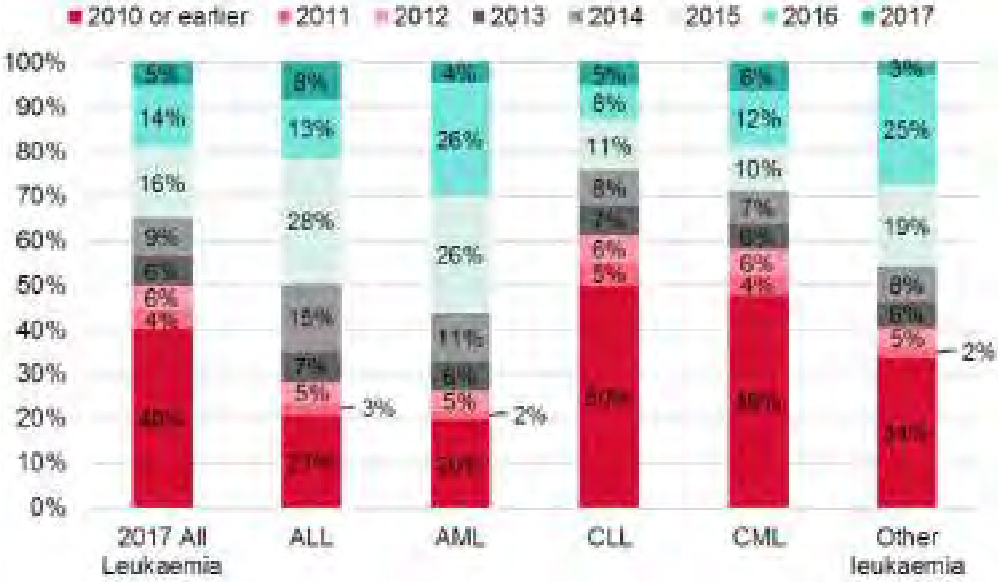


Figure 9: *Leukaemia type – by year of diagnosis*

There is a significant difference between the proportion of respondents with chronic leukaemia (CLL and CML) and acute leukaemia (ALL and AML) who were diagnosed before 2010.

This is broadly consistent with the known survival expectancies of each condition. Data from the NCIN (National Cancer Intelligence Network) suggests that around 20% of AML patients will survive their leukaemia for five years or more after their diagnosis. The chronic nature of certain leukaemia types means that patients will live with an incurable condition for many years.

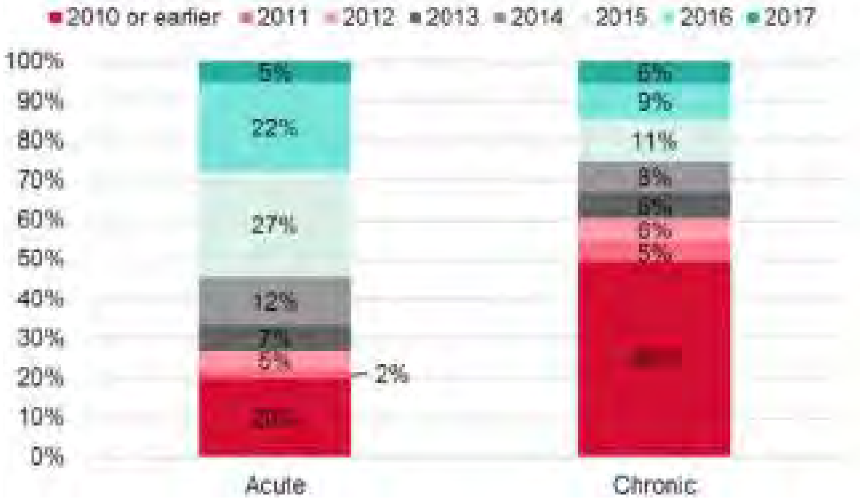


Figure 10: *Acute and chronic leukaemia*

In addition, the following charts illustrate what percentage of respondents from each year came from each arm of the survey and contained acute or chronic patients.

Results from patients reporting their diagnosis in 2017 may have a bias due to the greater percentage coming from Arm 3.

Figure 11: *Year of diagnosis – by patient cohort*

Consideration should also be made of variance that may be caused by the proportion of respondents who were either acute or chronic patients, as they can report different experiences due to the nature of their disease.

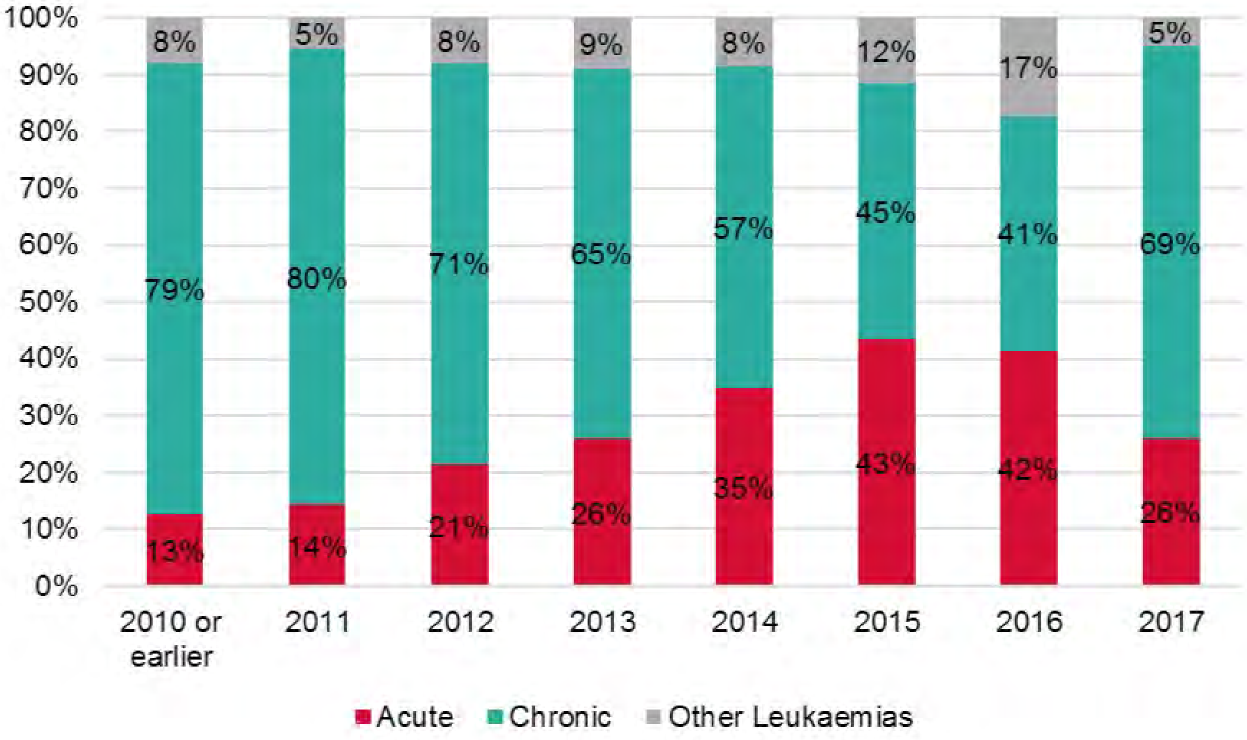
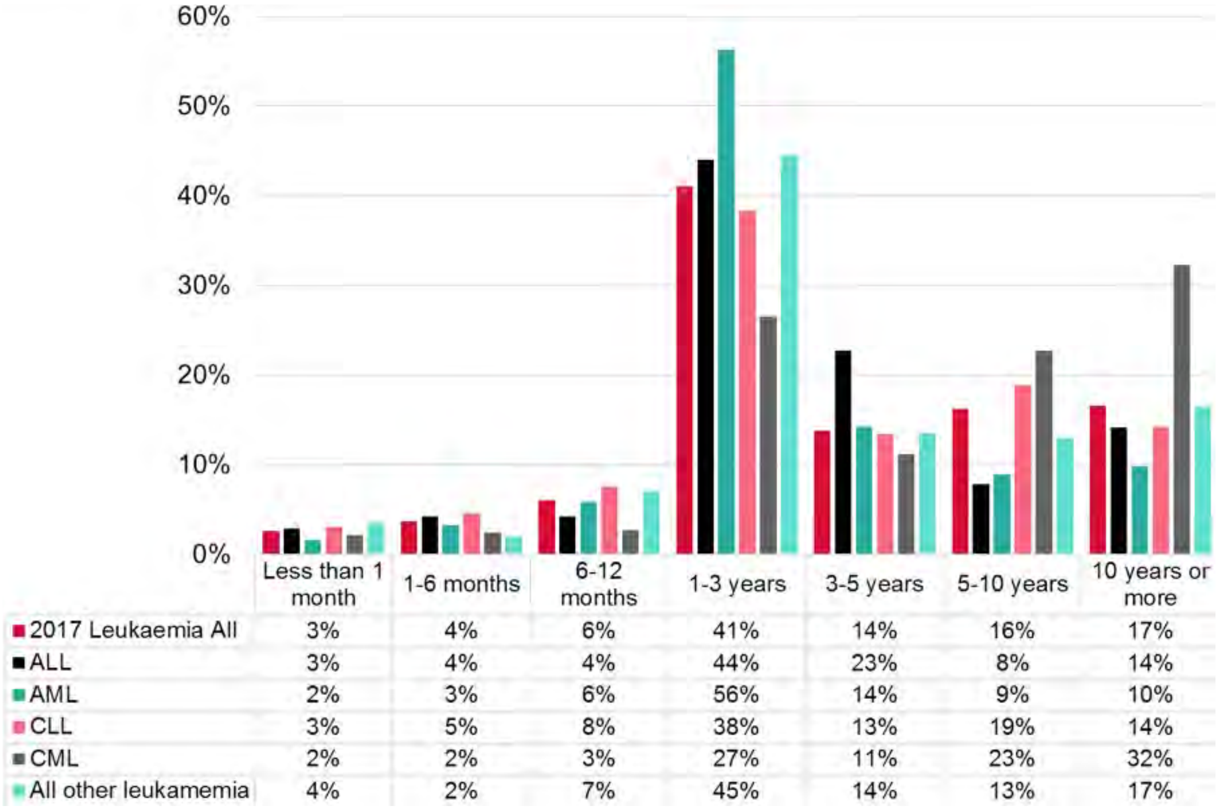


Figure 12: *Year of diagnosis – by acute, chronic and other leukaemias*

4.1.9 Time since first started treatment

The chart below illustrates the spread of responses for the time elapsed since patients first started treatment. For nearly all leukaemia types the most common answer was between 1-3 years; however, for CML the most common response was 10 or more years.



	Less than 1 month	1-6 months	6-12 months	1-3 years	3-5 years	5-10 years	10 years or more
🟥 2017 Leukaemia All	3%	4%	6%	41%	14%	16%	17%
■ ALL	3%	4%	4%	44%	23%	8%	14%
🟩 AML	2%	3%	6%	56%	14%	9%	10%
■ CLL	3%	5%	8%	38%	13%	19%	14%
■ CML	2%	2%	3%	27%	11%	23%	32%
■ All other leukamemia	4%	2%	7%	45%	14%	13%	17%

Figure 13: *Time since first started treatment*

4.2 Before diagnosis

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

4.2.1 Symptoms experienced

Blood cancers may cause numerous different symptoms. We asked what symptoms respondents experienced before their diagnosis of leukaemia, requesting they select all that applied.

The most frequently experienced symptom was fatigue (56%), followed by feeling weak or breathless (34%) and then fever / night sweats (31%). 15% of respondents encountered no symptoms prior to their diagnosis.

The chart below shows the full range of replies:

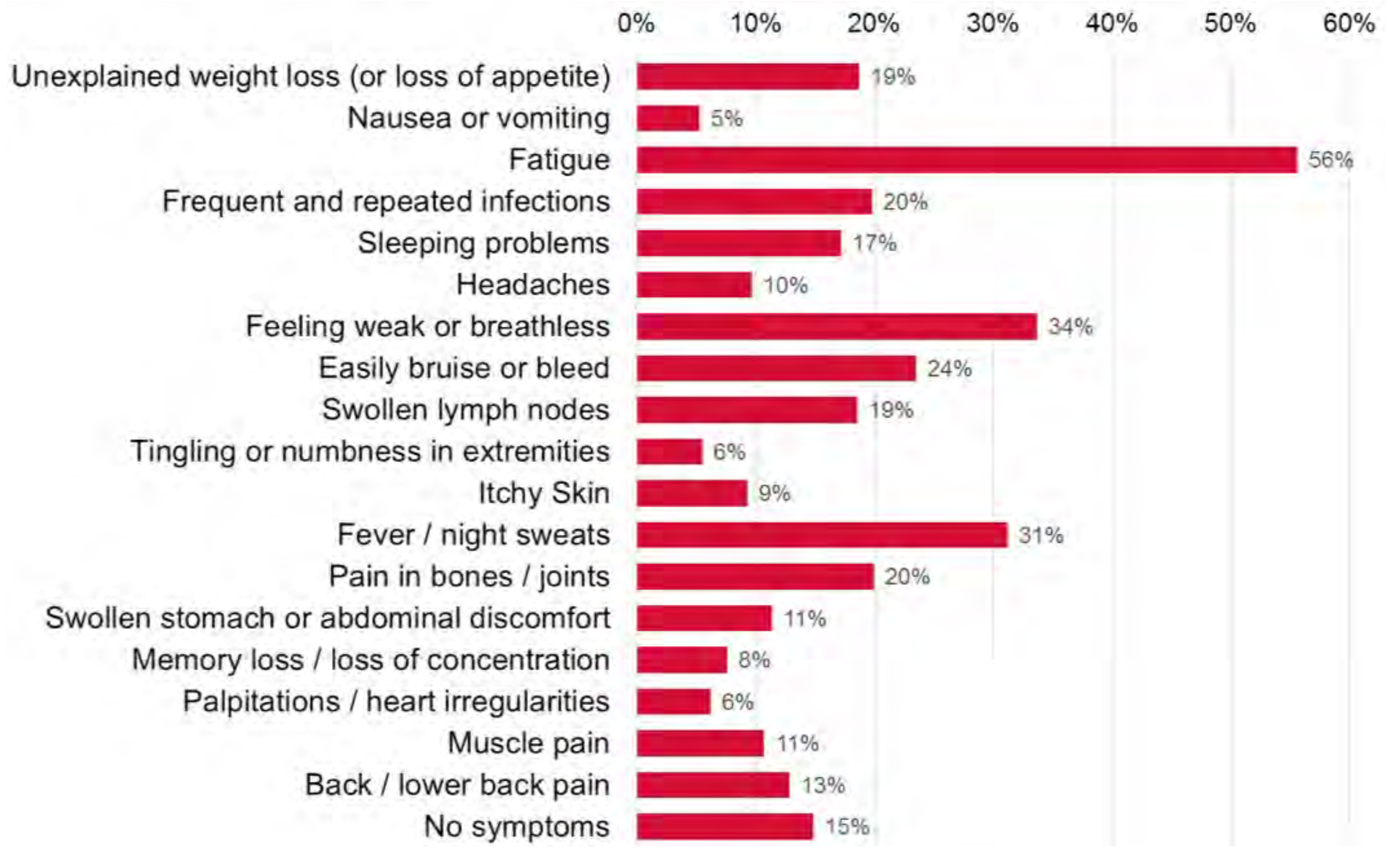


Figure 14: *Symptoms experienced prior to diagnosis*

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

ALL

Fatigue 77%
Feeling weak or breathless 64%
Fever/night sweats 42%
Easily bruise or bleed 41%
Unexplained weight loss (or loss of appetite) 31%

CLL

Fatigue 43%
Swollen lymph nodes 32%
Fever/night sweats 27%
No symptoms 22%
Feeling weak or breathless 19%

Other Leukaemia

Fatigue 62%
Feeling weak or breathless 39%
Easily bruise or bleed 33%
Fever/night sweats 33%
Pain in bones/joints 21%

AML

Fatigue 69%
Feeling weak or breathless 55%
Easily bruise or bleed 35%
Fever/night sweats 27%
Pain in bones/joints 23%

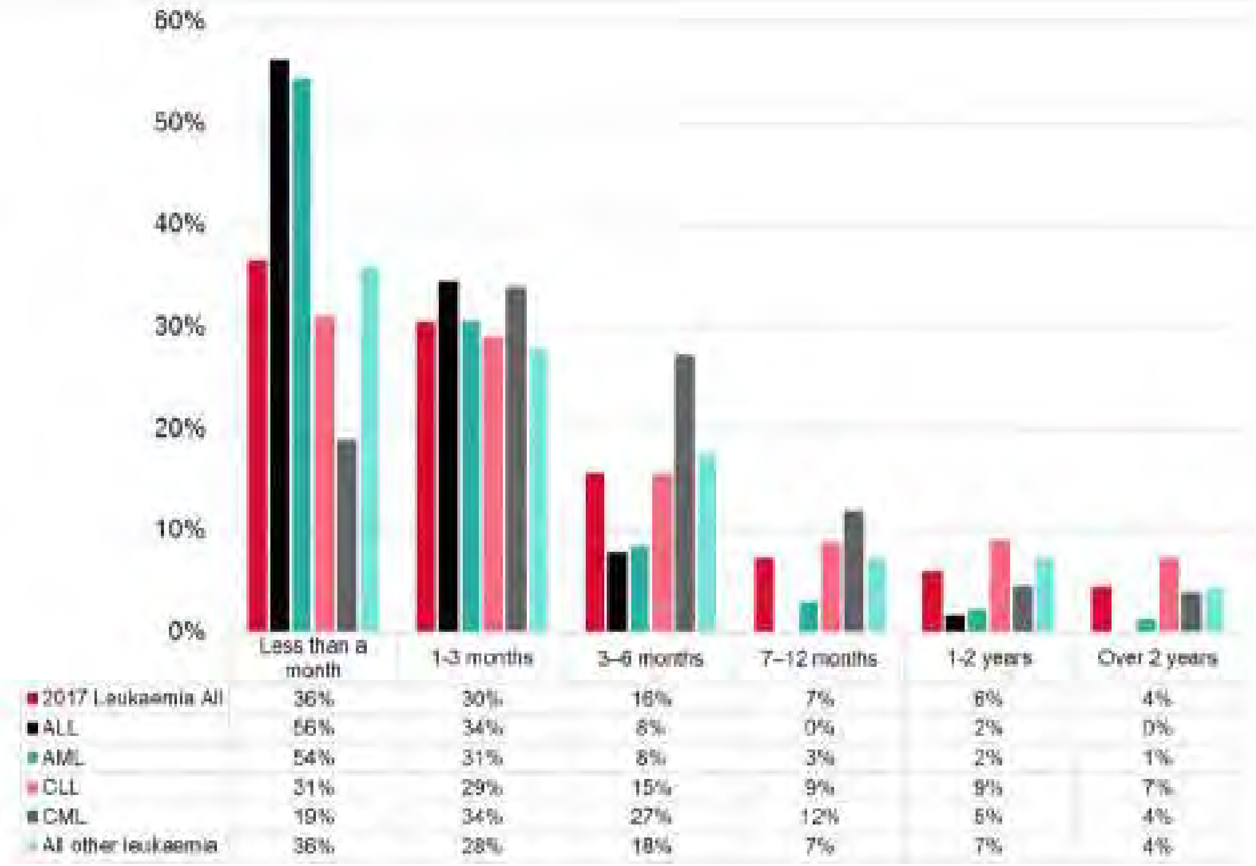
CML

Fatigue 65%
Fever/night sweats 45%
Feeling weak or breathless 37%
Unexplained weight loss (or loss of appetite) 35%
Pain in bones/joints 32%

This question was also asked in the 2016 survey, and the results were used to shape Leukaemia Care's successful and ongoing 'Spot Leukaemia' campaign, helping raise awareness of the signs and symptoms of the different types of leukaemia www.leukaemiacare.org.uk/get-involved/our-campaigns/spotleukaemia/

4.2.2 Time from experiencing symptoms until seeing a healthcare professional

There are some big differences around the time respondents waited from experiencing symptoms to visiting a healthcare professional, depending on leukaemia type. This is particularly apparent within the 'less than one month' response.



	Less than a month	1-3 months	3-6 months	7-12 months	1-2 years	Over 2 years
■ 2017 Leukaemia All	36%	30%	16%	7%	6%	4%
■ ALL	56%	34%	8%	0%	2%	0%
■ AML	54%	31%	8%	3%	2%	1%
■ CLL	31%	29%	15%	9%	9%	7%
■ CML	19%	34%	27%	12%	5%	4%
■ All other leukaemia	36%	28%	18%	7%	7%	4%

Figure 15: *Time until saw healthcare professional - by leukaemia type*

There are clear differences between acute (ALL, AML) and chronic (CLL, CML) leukaemia.

As the chart below illustrates, a significantly higher percentage of acute respondents (55%) visited a health professional less than a month after experiencing symptoms, compared to 27% of chronic respondents. This is likely to be due to the significant symptom burden experienced by acute leukaemia patients. Chronic respondents are more likely to wait longer before visiting a health professional and there is a significant difference between those waiting 3-6 months compared to acute patients. However, the importance of early diagnosis is relevant regardless of leukaemia type, and therefore the awareness of symptoms for any leukaemia type is key.

Figure 16: *Time until saw healthcare professional - by acute and chronic leukaemia types*

4.2.3 Route to diagnosis

We asked respondents to select their initial route to being diagnosed with a blood cancer.

The charts below illustrate the reported routes to diagnosis across the different leukaemia types, with comparisons to how this was reported in 2016.

- Acute leukaemia patients remain more likely to be sent straight to hospital on the same day, or be an emergency or A&E patient
- Patients with chronic leukaemia are still more likely to be seen via an urgent referral (two-week wait)
- CLL patients continue to wait longer as they are more likely to have been seen via a non-urgent referral

These findings remain consistent with the NCIN Routes to Diagnosis report.

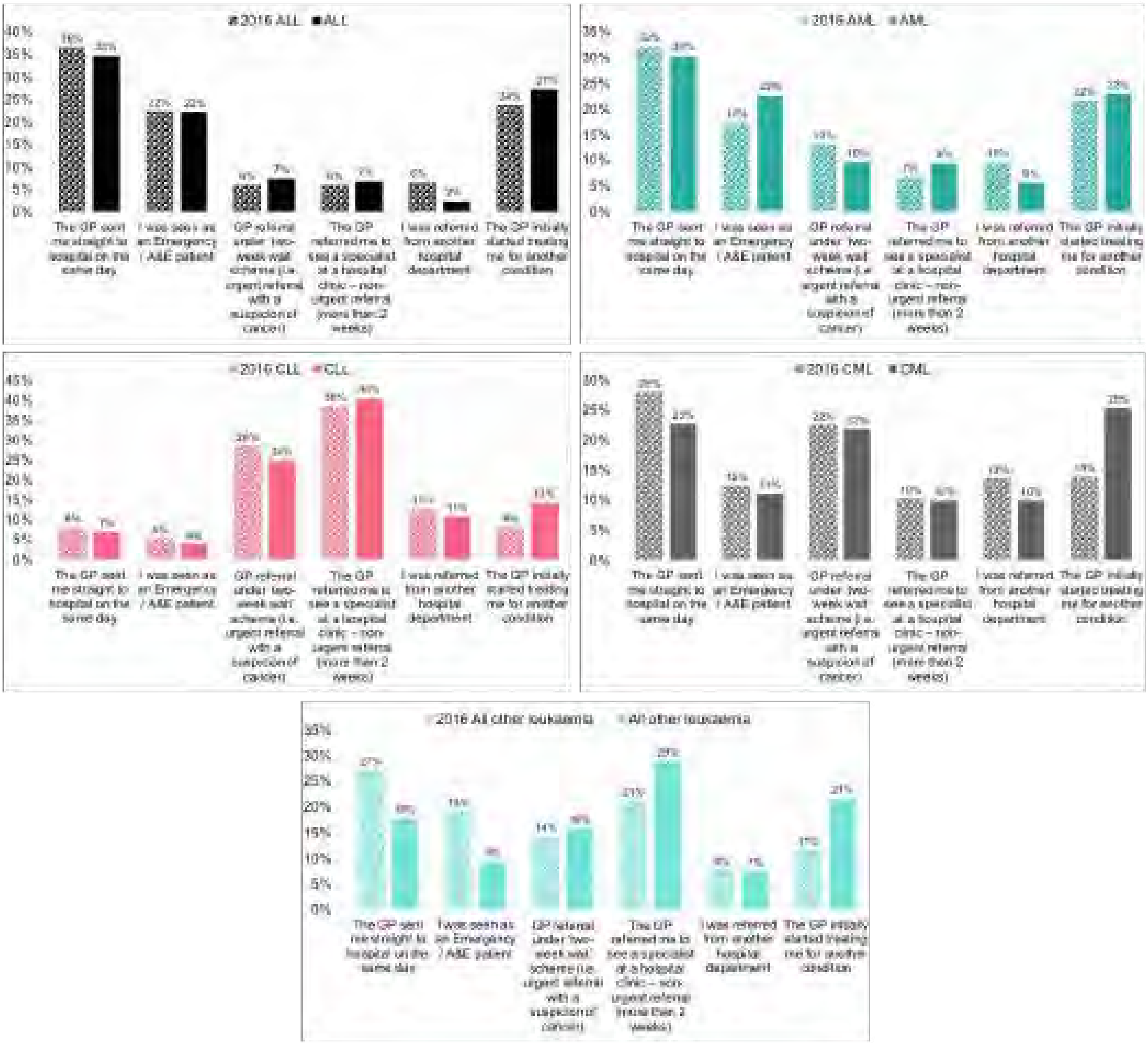


Figure 17: *Route to diagnosis by leukaemia type*

We looked at how respondents described their route to diagnosis in relation to when they said they were diagnosed. The results are split between acute and chronic patients as there is often a difference in route to diagnosis, as the charts illustrate. For acute patients, the trendlines suggest an increase in emergency admissions and decrease in emergency referrals. For chronic patients there is also the indication of a greater proportion coming through A&E, but a decrease of those coming through another hospital department.

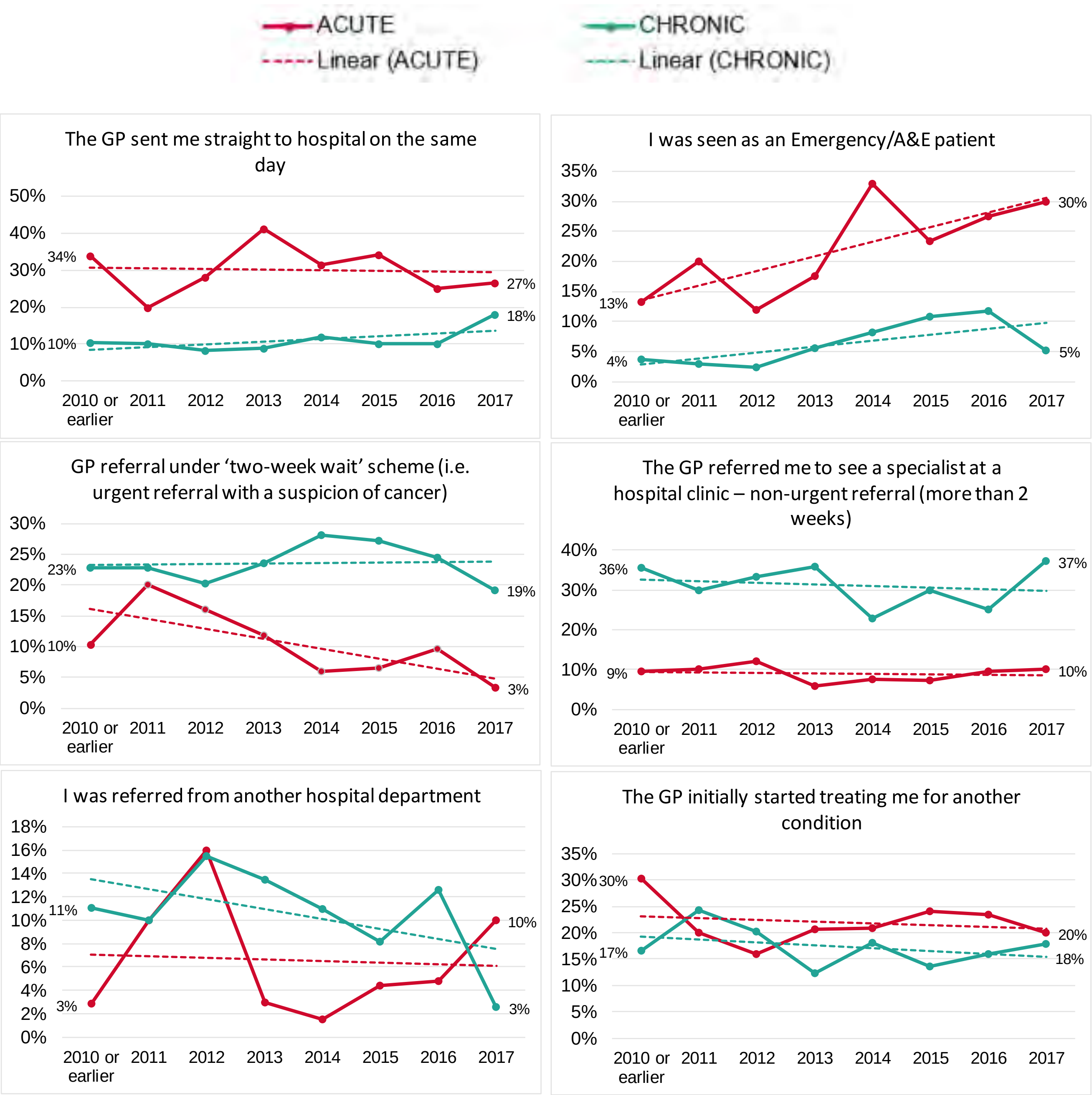


Figure 18: *Route to diagnosis for acute/chronic leukaemias - by year of diagnosis*

4.2.4 GPs' understanding of blood cancers

The following chart shows how much understanding respondents felt their GP had about blood cancers. Just under half of respondents (48%) felt their GP had a complete understanding, with over a third (38%) saying they only had a partial understanding, and 14% felt their GP did not seem to know about blood cancers.

In addition, chronic patients were less likely to say their GP had a complete understanding of blood cancers compared to acute patients (45% chronic, 55% acute), and more likely to say they had a partial understanding (41% chronic, 27% acute).

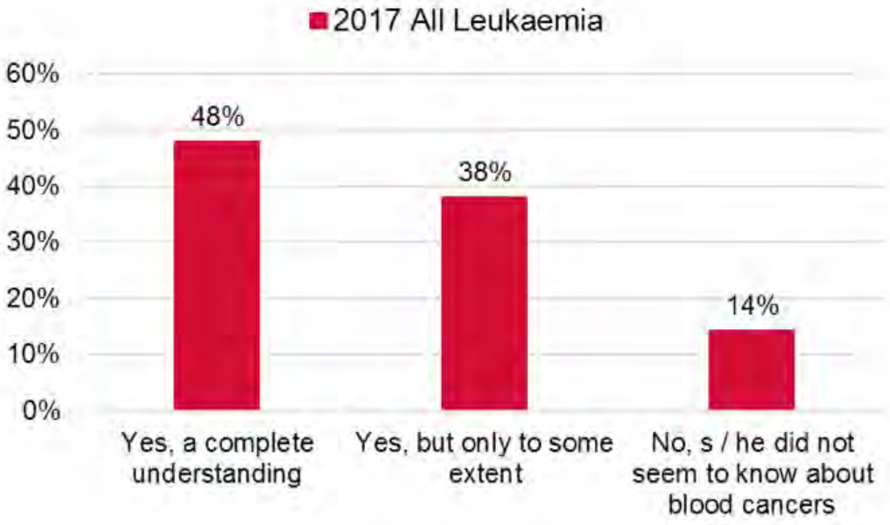


Figure 19: *GPs' understanding of blood cancers*

The chart below illustrates how respondents answered this question depending on their year of diagnosis. 2017 respondents are more negative than previous years, but as previously noted this is likely to be influenced by the higher percentage of these patients being derived from Arm 3. However, even if we disregard 2017 results, the trendline indicates that patients' perceptions of GPs having a complete understanding of blood cancers is static.

This indicates the need for continued work to educate and support GPs on blood cancers. Leukaemia Care has been implementing this through various channels including: collaboration with the Royal College of General Practitioners (RCGP) to create eLearning modules, in person training events around the country, and the 'Spot Leukaemia' campaign.

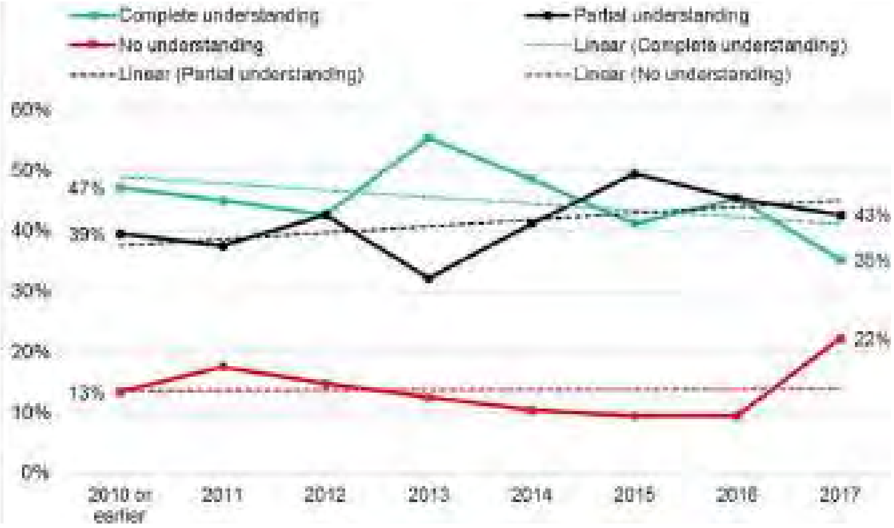


Figure 20: *GPs' understanding of blood cancers - by year of diagnosis*

4.2.5 Number of GP visits before referral to hospital

A quarter of respondents went to their GP more than twice before being referred to secondary care; this result is similar to the 'all haematology' patients surveyed in the CPES 2016 survey (23%). AML respondents were more likely to say they needed to see their GP more than twice before referral (31%).

Looking at this question by year of diagnosis, overall there has been little change.

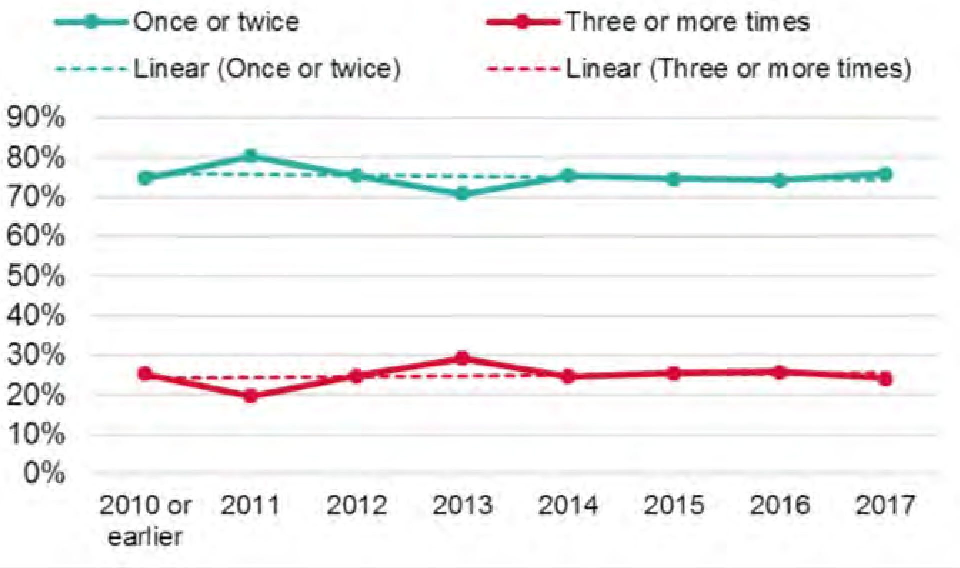
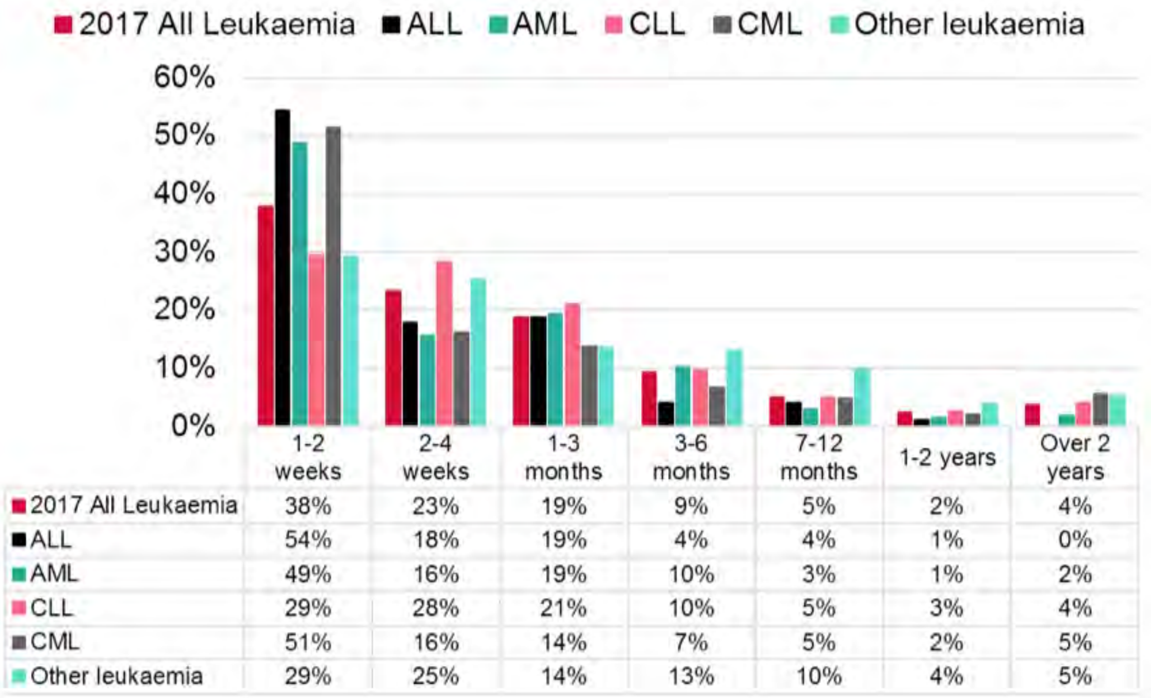


Figure 21: *Number of visits to GP before referral - by year of diagnosis*

4.2.6 Length of time from seeing GP to blood cancer diagnosis

We asked respondents how long it was from the time they first saw a GP until they received their blood cancer diagnosis. ALL, AML and CML patients were more likely to report a quicker diagnosis of 1-2 weeks, significantly quicker when compared to CLL and 'Other leukaemia'. However, after 4 weeks the differences are less pronounced.



	1-2 weeks	2-4 weeks	1-3 months	3-6 months	7-12 months	1-2 years	Over 2 years
2017 All Leukaemia	38%	23%	19%	9%	5%	2%	4%
ALL	54%	18%	19%	4%	4%	1%	0%
AML	49%	16%	19%	10%	3%	1%	2%
CLL	29%	28%	21%	10%	5%	3%	4%
CML	51%	16%	14%	7%	5%	2%	5%
Other leukaemia	29%	25%	14%	13%	10%	4%	5%

Figure 22: *Number of visits to GP before referral - by leukaemia type*

4.2.7 Respondents expectations of what was wrong

Respondents were asked if they thought they might have cancer before they were diagnosed. There is little change by year of diagnosis: 81% of respondents diagnosed in 2010 or earlier did not think it would be cancer at all, compared to 78% in both 2016 and 2017. Overall, the 2017 results show that 79% of patients did not think it would be cancer, 4% expected it to be cancer and 17% had some suspicions that they may have cancer.

4.3 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.

4.3.1 Respondents understanding that their diagnosis was a type of cancer

Overall, 68% of respondents said that they were aware that their diagnosis was a type of cancer, 12% weren't sure that it was cancer, but they thought it might be, and 20% reported that they did not know their diagnosis was a type of cancer. While those diagnosed in 2017 were less likely to not know their diagnosis was a form of cancer, the trendline over time shows little change.

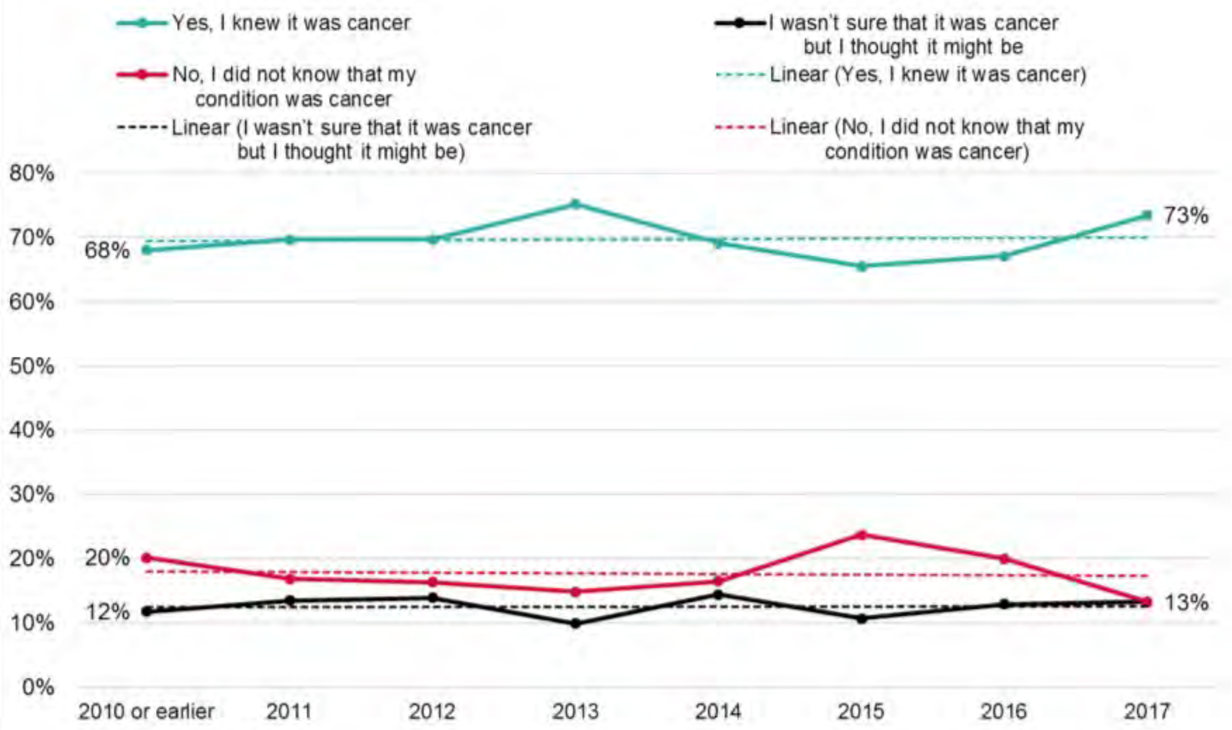


Figure 23: *Respondents' understanding of their diagnosis - by year of diagnosis*

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

Respondents were asked if, at their first hospital appointment, they were told about their blood cancer subtype. While the overall score is high (86%) there are some significant differences between leukaemia types. In particular, ALL and patients with an 'Other leukaemia' are less likely to be told.

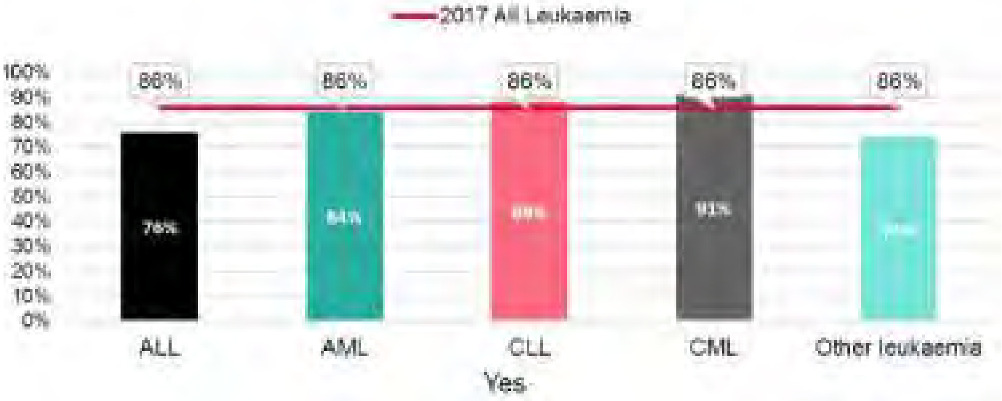


Figure 24: *Respondents were told about their blood cancer subtype - by leukaemia type*

4.3.3 Understanding the explanation of what was wrong

When asked if they understood the explanation of what was wrong with them, 43% said they completely understood, 49% said they understood some of it, and 8% did not understand the explanation of what was wrong with them.

Respondents from Arms 2 and 3 were significantly less likely to say that they completely understood the explanation of what was wrong with them (36%, compared to 50% Arm 1). This supports our findings in 2016, indicating patients with a lack of understanding of their diagnosis are more likely to reach out to charities for additional information and support. Looking at the question across the different years of diagnosis, there has been a gradual improvement of patients having a complete understanding and decline in partial or no understanding. The overall change between complete understanding in 2010 or earlier (40%), and 2016 (50%) is significant. The dip in 2017 is likely to be influenced by the number of patients in this group that came from the Arm 3 cohort.

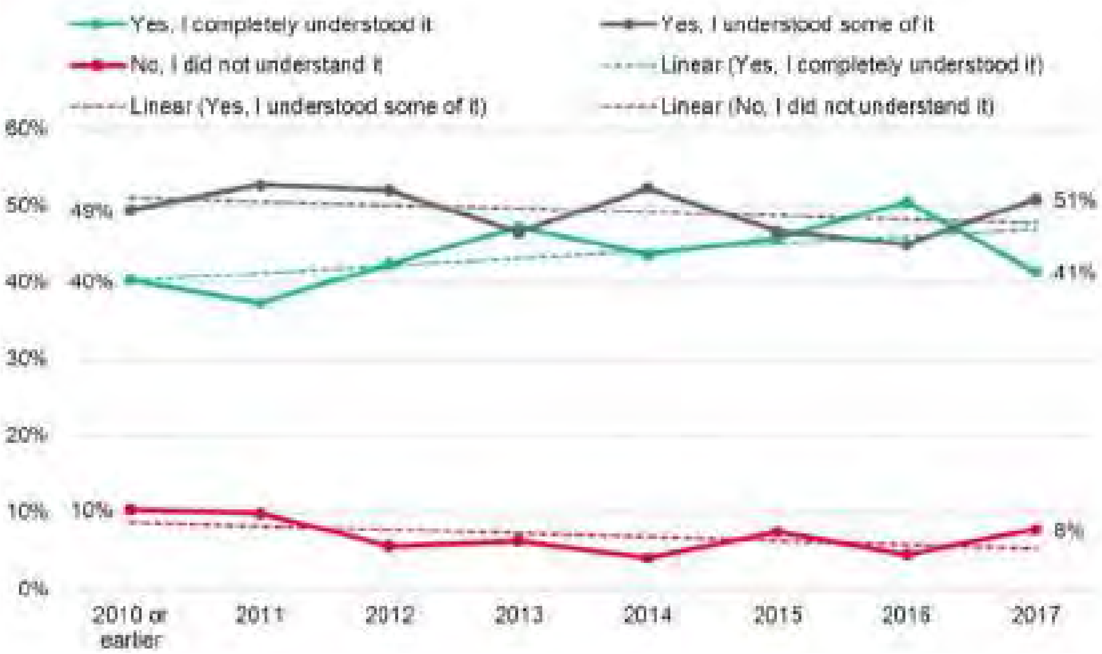


Figure 25: *Respondents' understanding of the explanation of diagnosis – year of diagnosis*

4.3.4 How diagnosis information was first delivered

In the 2017 survey we asked patients how their diagnosis was given to them, whether this information came from the hospital or from their GP, and if it was delivered in person or over the phone.

Most respondents reported being told in person, and most were told at the hospital.

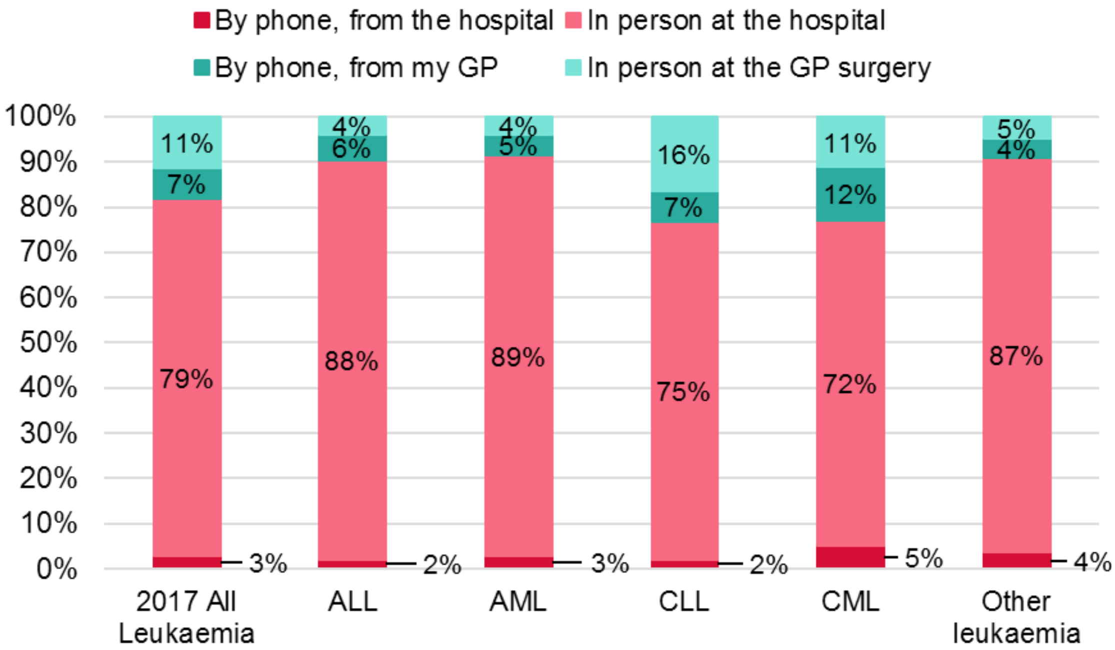


Figure 26: *Diagnosis delivery method – by leukaemia type*

However, chronic patients were more likely to be told over the phone and more likely to be told by someone within the GP setting.

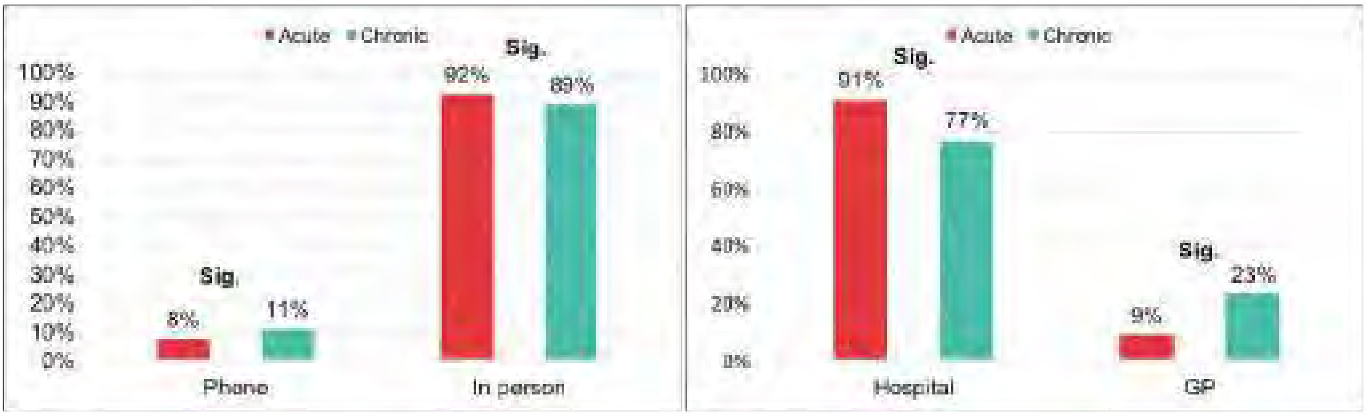


Figure 27: *Diagnosis delivery method – by acute and chronic leukaemia*

4.3.5 Accompanying person at diagnosis

There is little difference in reported accompaniment at diagnosis responses. As in 2016, although most respondents did take someone with them, there is still a large proportion (39%) who do not.

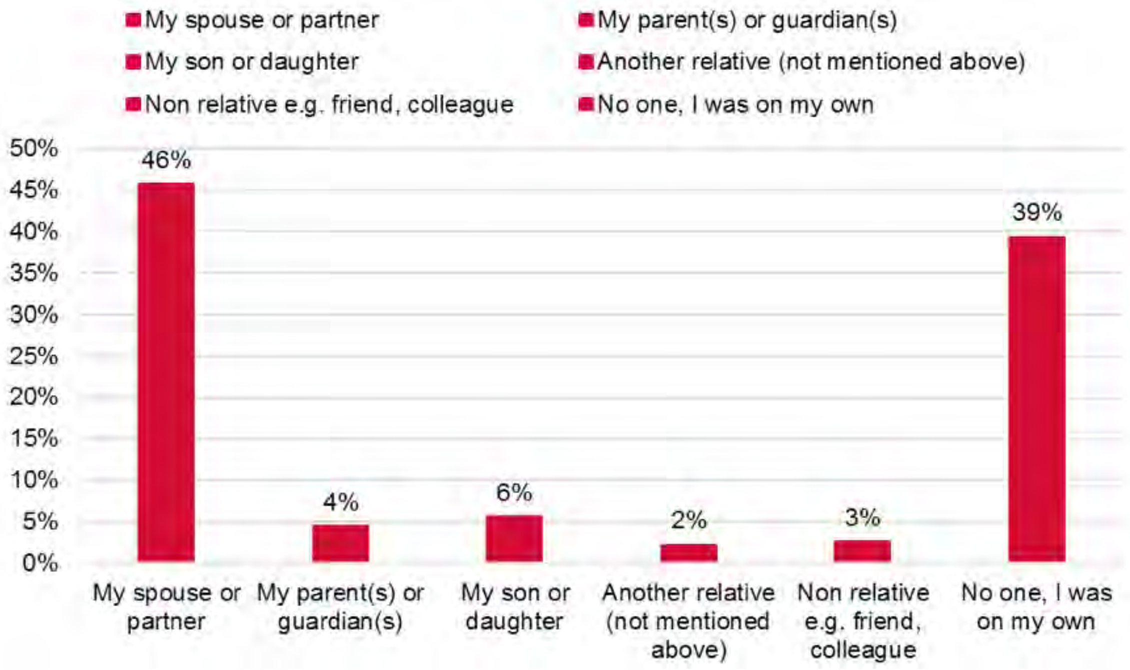


Figure 28: *Accompanying person at diagnosis*

The year of diagnosis chart below illustrates how the percentage of patients accompanied at diagnosis has improved. The changes between 2010 or earlier, and 2016 are significant.

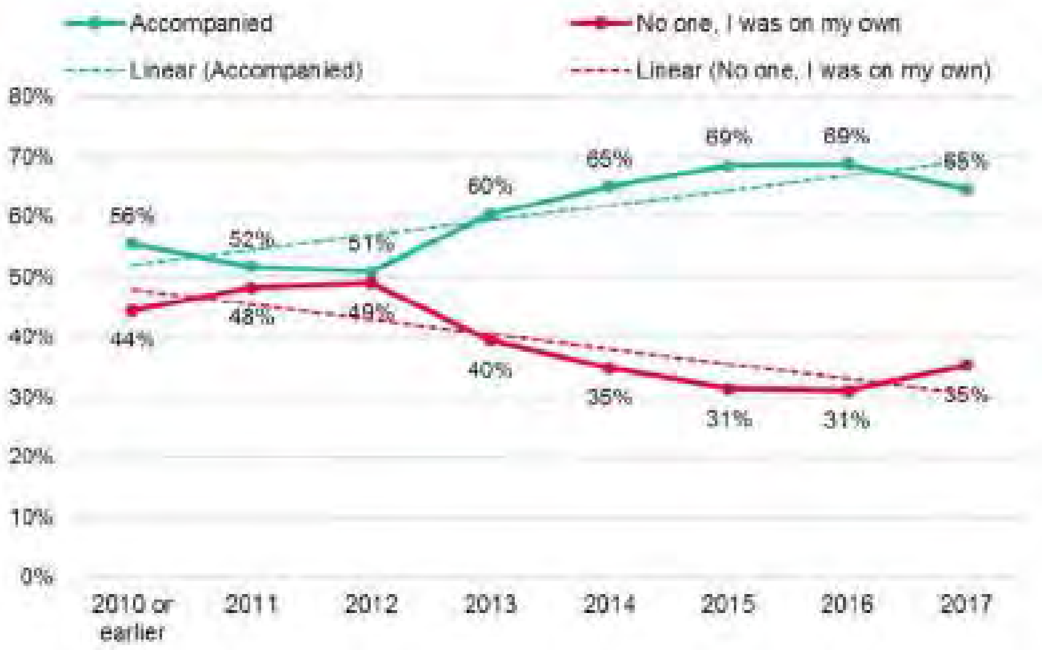


Figure 29: *Accompanied at diagnosis – by year of diagnosis*

There continues to be some clear differences in the proportion of unaccompanied respondents by leukaemia type. In particular, chronic leukaemia patients are significantly more likely to be unaccompanied compared to acute patients – 45% chronic and 26% acute.

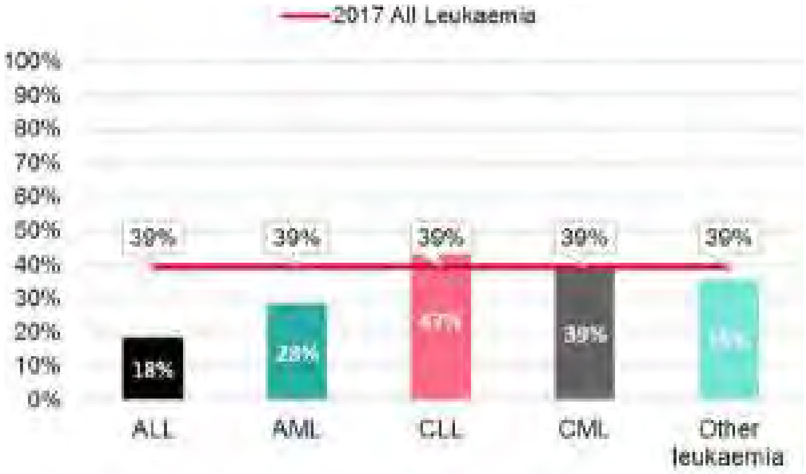


Figure 30: *Respondents unaccompanied to their diagnosis meeting - by leukaemia type*

4.4 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.

4.4.1 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 (75%) said that they were definitely involved as much as they wanted, 20% were involved to some extent and 5% replied that no, they were not involved as much as they wanted. There is little change between these scores and those in the 2016 survey and by year of diagnosis.

As in 2016 there were some significant differences in experiences between patients recruited from CPES and those through charities. 83% of Arm 1 felt they were definitely involved in decisions, compared to 69% of Arm 2, and 65% of Arm 3 as shown on the graph below.

Between leukaemia types, CML patients were least likely to say they had definitely been involved as much as they wanted to be (69%), significantly lower than the overall score.

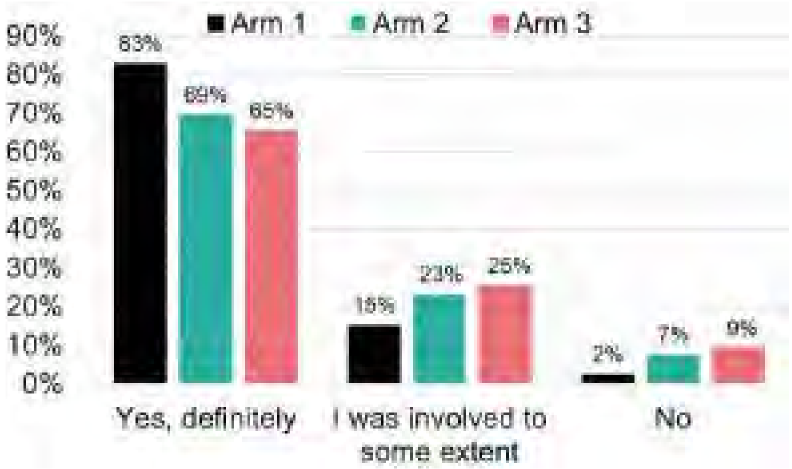


Figure 31: *Involvement in decisions about treatment and care - by patient cohort*

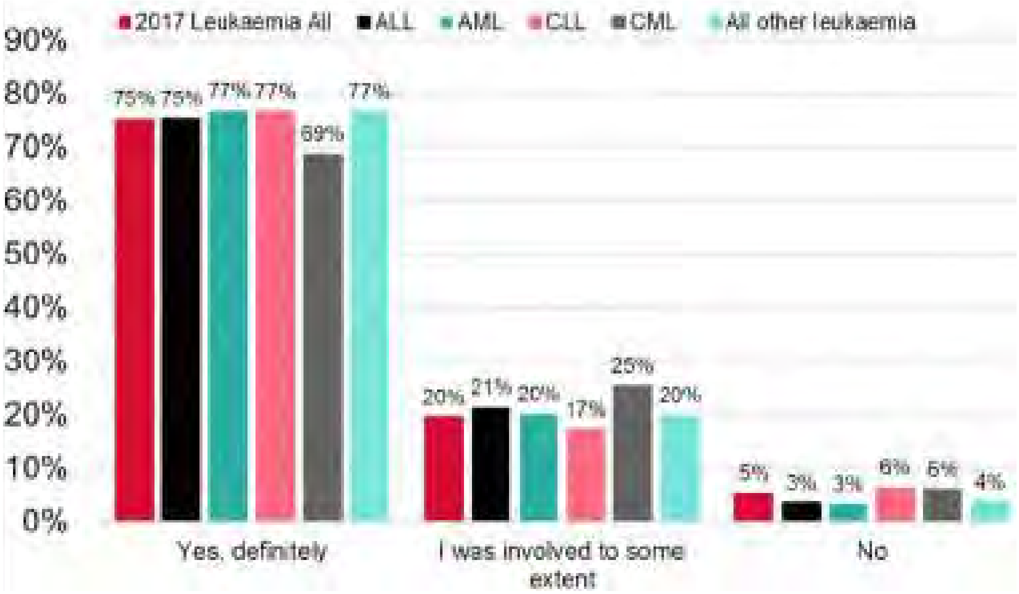


Figure 32: *Involvement in decisions about treatment and care - by leukaemia type*

4.4.2 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:

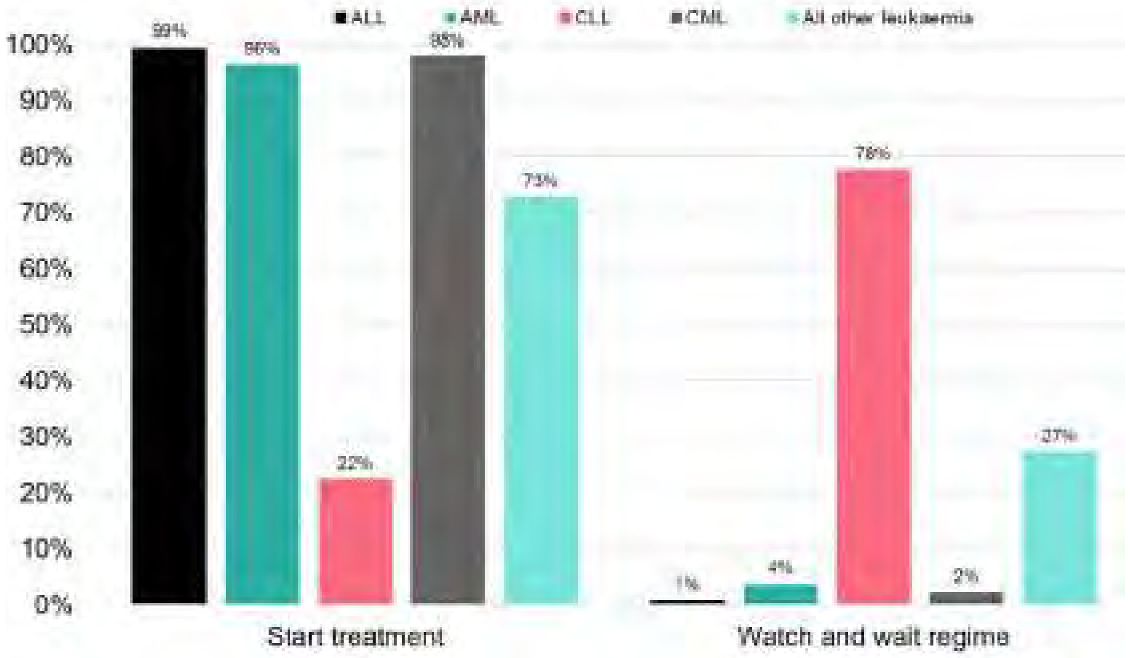


Figure 33: *Treatment vs 'watch and wait' - by leukaemia type*

Involvement in decisions about treatment and care - CLL breakdown

Once again we have carried out a more detailed analysis of the experience of CLL patients on ‘watch and wait’.

CLL patients who were on ‘watch and wait’ at some point in their treatment journey were significantly less likely to report feeling completely involved in decisions about their treatment and care, 75% compared to 83% who started treatment. In addition, 8% said they were not involved, compared to 2% who began treatment.

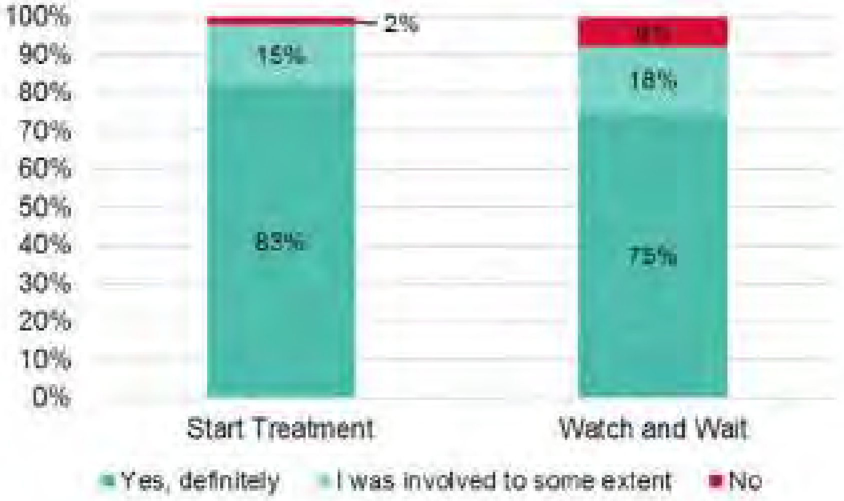


Figure 34: *Involvement in decision about treatment and care - by CLL ‘Watch and wait’*

CLL patients who are still on ‘watch and wait’ are even less positive about their involvment, as the chart below illustrates.

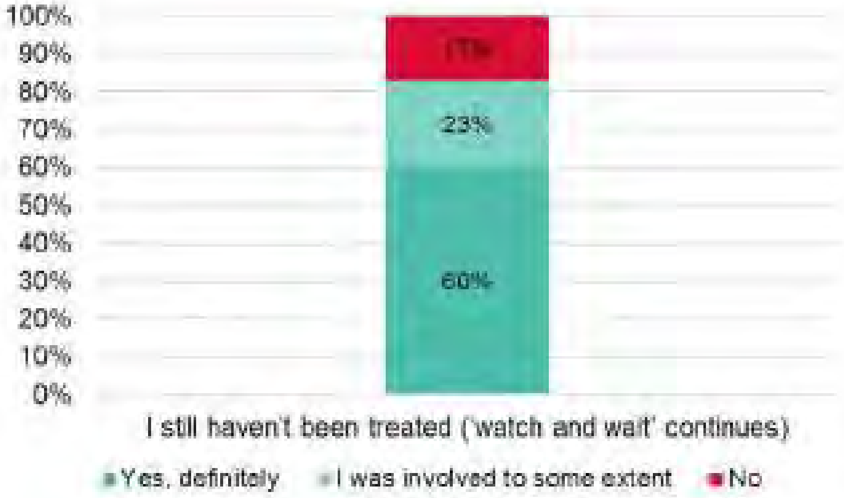


Figure 35: *Involvement in decision about treatment and care - by CLL still on ‘Watch and wait’*

4.4.3 Respondents' understanding of reasons for 'watch and wait'

Of those respondents who were placed on 'watch and wait', over half (60%) fully understood the reasons, a third (33%) mostly understood the reasons and just 7% did not understand the reasons. These scores are nearly identical to the 2016 survey.

As in the 2016 survey, there are differences between patient cohorts on this question. Respondents from Arms 2 and 3 (charity cohorts) reported not fully understanding the reasons they were put on 'watch and wait'. Patients from these arms are significantly less likely to fully understand the reasons than those from Arm 1. They are also significantly more likely to say they did not understand the reasons for being placed on 'watch and wait'. This supports the premise 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.

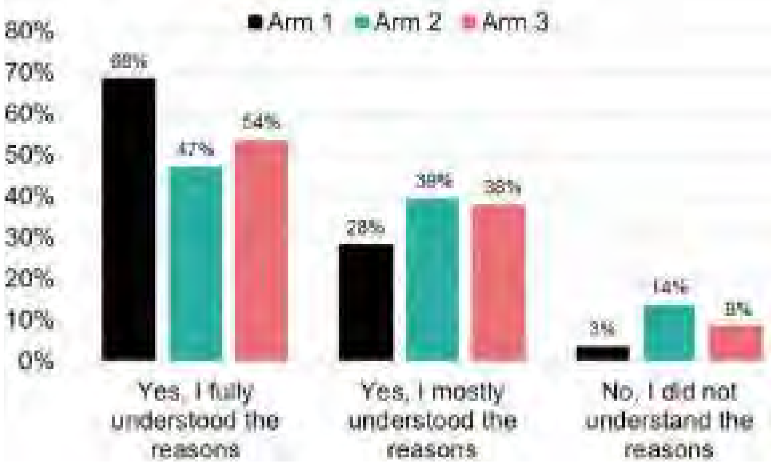


Figure 36: *Understanding of reasons for 'watch and wait' - by patient cohort*

4.4.4 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, and 11% said they were very concerned/worried. This shows no change from the 2016 survey.

As identified in the 2016 survey, respondents with no, or partial, understanding of the reasons for being placed on 'watch and wait' continue to be more likely to have concerns and worries.

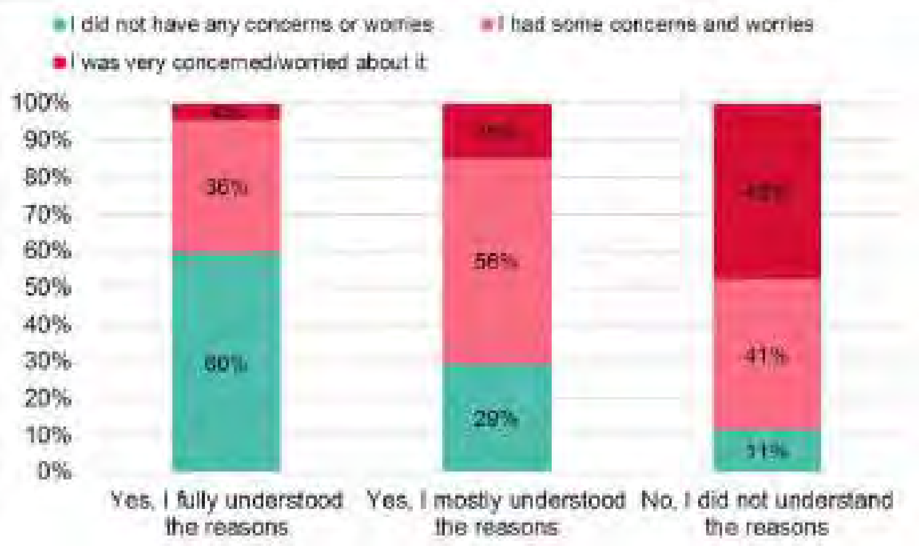


Figure 37: *Concerns around 'watch and wait' - by understanding of reasons for 'watch and wait'*

In addition, there continues to be a big difference between patient cohorts, as 39% of the Arm 2 respondents, and 35% of the Arm 3 respondents, did not have any concerns about being on ‘watch and wait’, significantly lower than Arm 1 respondents (57%). Respondents from the ‘charity’ arms were also significantly more likely to say they were very concerned / worried than those from Arm 1.

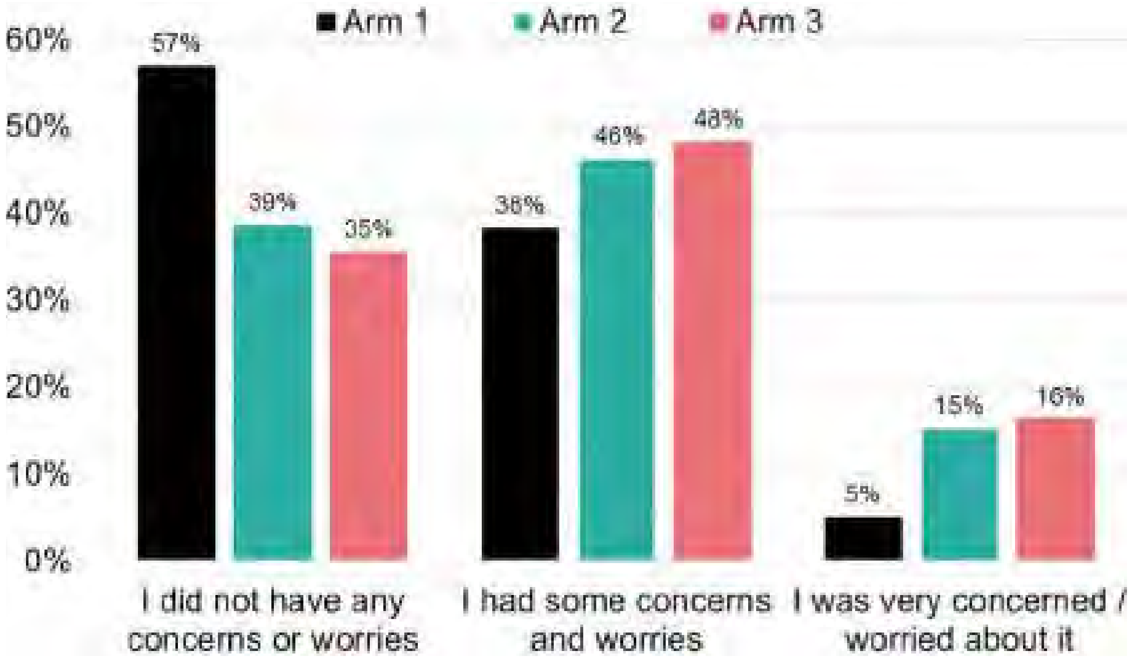


Figure 38: *Concerns around ‘watch and wait’ - by patient cohort*

These results clearly demonstrate 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.

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 live chat facility and support helpline, providing emotional and practical support as well as medical advice.

4.4.5 Written information on ‘watch and wait’

Of those who felt they needed written information on ‘watch and wait’, 55% of respondents were given it, and felt it was easy to understand. Just over a third of respondents (35%) were not given any written information about their ‘watch and wait’ regime.

The 2017 results, as seen below, support our 2016 findings that the level/quality of written information given to patients about ‘watch and wait’ relates to how worried they then feel about being placed on this form of active monitoring.

Respondents receiving understandable written information are much more likely not to have any concerns or worries, and patients being given information that they find difficult to understand has a more negative effect than being given no information at all.

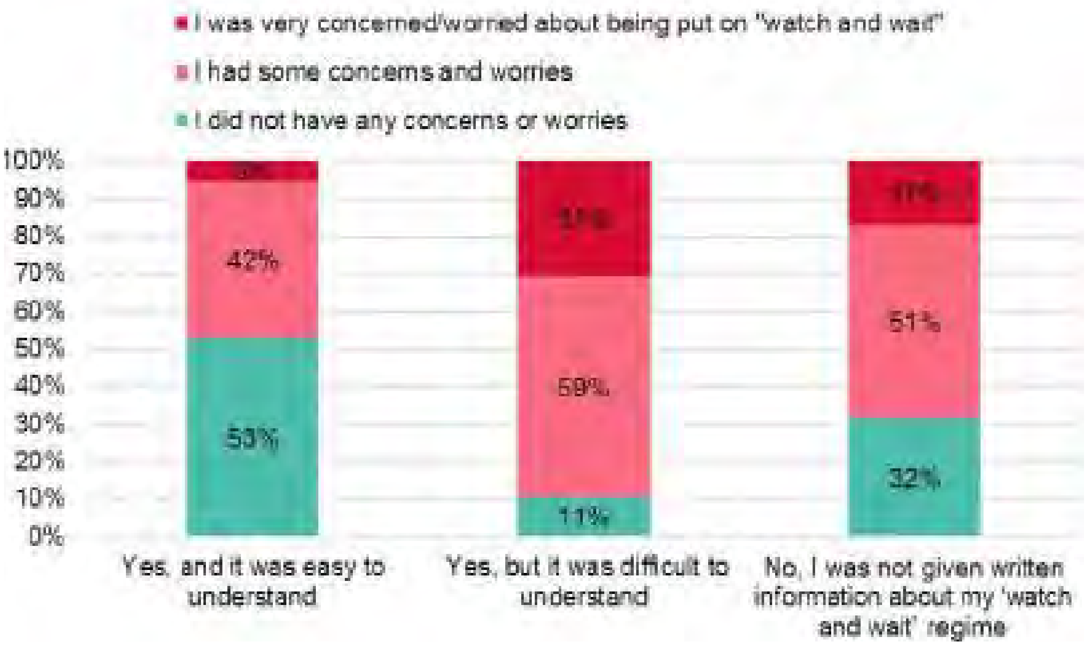


Figure 39: *Concerns around ‘watch and wait’ - by quality/quantity of written information given*

4.4.6 Length of time on ‘watch and wait’

We asked respondents how long they were on ‘watch and wait’ before they started treatment. The chart below shows the full set of responses with CLL compared to non-CLL patients who are on ‘watch and wait’.

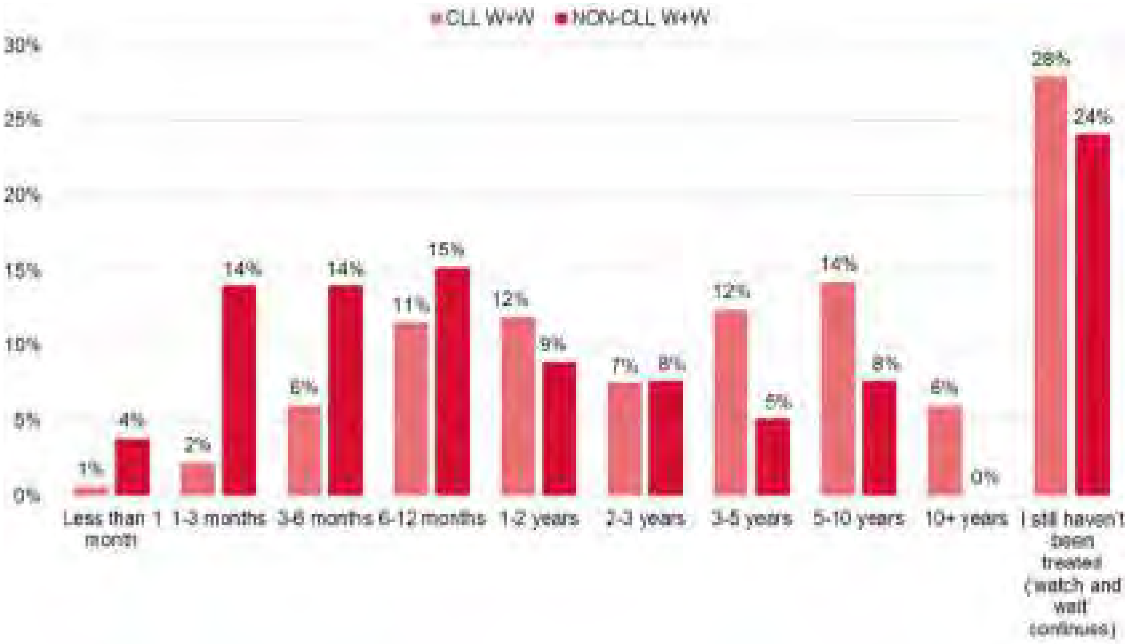


Figure 40: *Length of time on ‘watch and wait’*

The chart below illustrates the difference of time on ‘watch and wait’ between CLL patients and non-CLL patients (of those who have now started treatment). CLL patients are much more likely to have been in active monitoring for a longer time.

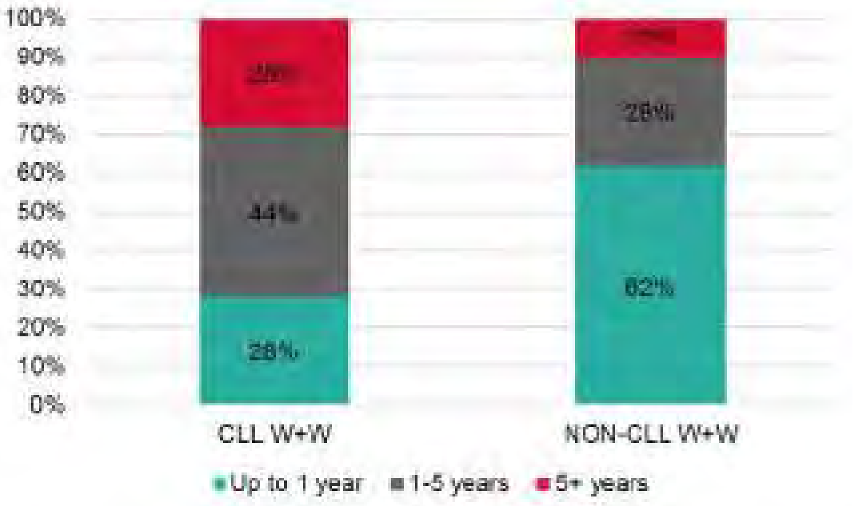


Figure 41: *Length of time on ‘watch and wait’ – by CLL and non CLL respondents*

Results from this section of the 2016 Survey were used by Leukaemia Care to inform the targeted campaign ‘Watch, Wait, Worry’, with the aim of improving the support offered to patients on ‘watch and wait’:
www.leukaemiacare.org.uk/get-involved/our-campaigns/watch-wait-worry/

4.4.7 Feelings upon starting treatment

Respondents were asked how they felt about having to start treatment. Overall, over a third (36%) categorised their feelings as positive, 12% felt negative and the majority (44%) felt a mixture of both. A smaller proportion (8%) reported feeling neutral / resolved about starting. Respondents who had been on 'watch and wait' were slightly more likely to report being positive/relieved about starting treatment.

Respondents from the 'charity' Arms 2 and 3 were significantly less likely to say they felt positive about starting treatment (29%) compared to those from Arm 1 (41%). They were more likely to say they felt mixed emotions (48% Arms 2 and 3, 40% Arm 1).

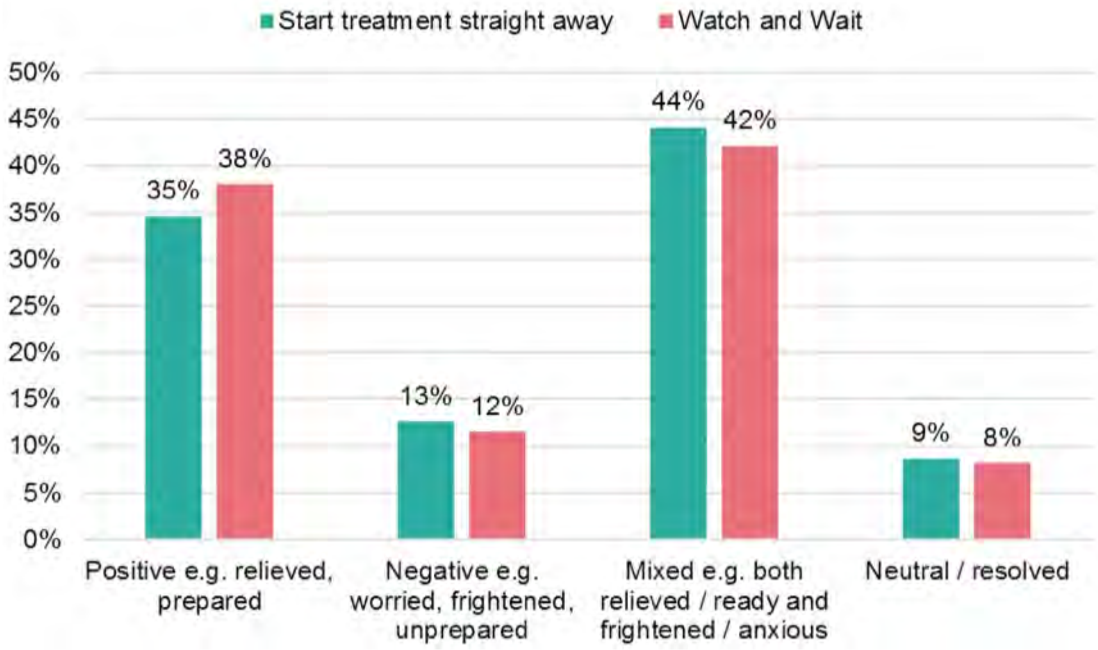


Figure 42: *Feelings upon starting treatment by treatment journey*

4.4.8 Length of time from diagnosis to start of treatment for specific blood cancer type

We asked respondents how long it was from their diagnosis to when they started treatment for their specific cancer type.

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; 21% of the CLL respondents reported waiting longer than two years.

The other leukaemia groups reported a much shorter wait from diagnosis to treatment, with the majority starting treatment the same day, or within two weeks of diagnosis.

4.4.9 Treatment options

As in the 2016 survey, respondents were asked if they were offered a choice of treatment options. There has been little change with just 32% (31% in the 2016 survey) saying they were given a choice, whilst 68% (69% in the 2016 survey) said that they were not given a choice.

As observed in last year's survey, 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.

The question remains around why patients are not being presented with a choice of different options when it is known that choices are available. One theory is that clinicians may inform patients of several options but recommend a particular one, leading patients to therefore not consider the other avenues available as potential choices for them.

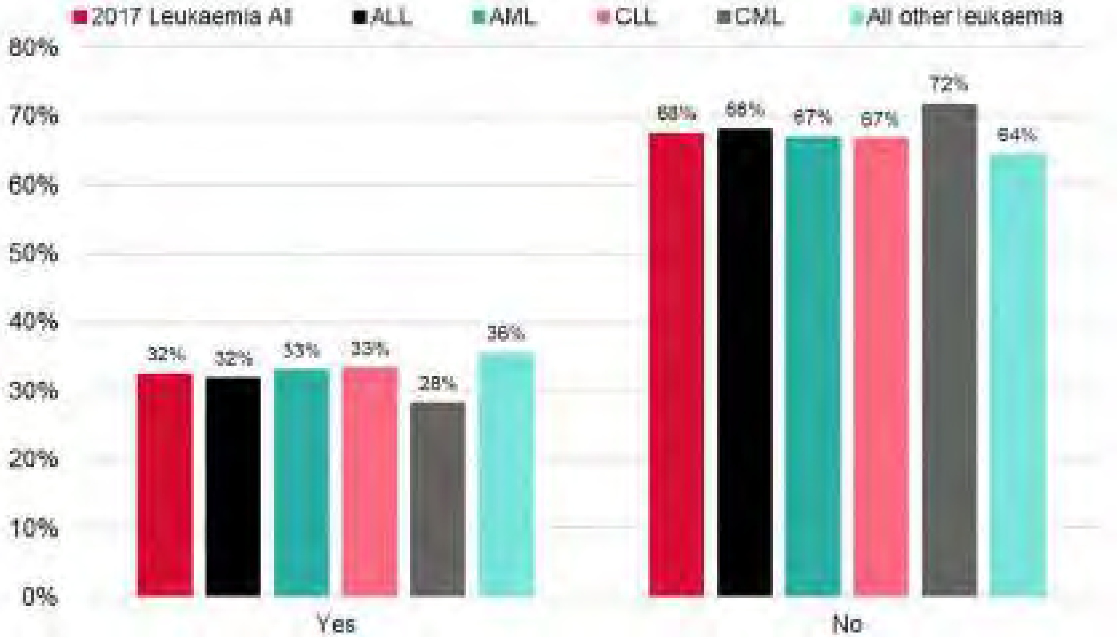


Figure 43: *Offered a choice of treatment options - by leukaemia type*

4.4.10 Treatment methods

A new question for 2017 was to ask patients which treatment methods they are using or have previously received. We allowed respondents to tick all that applied.

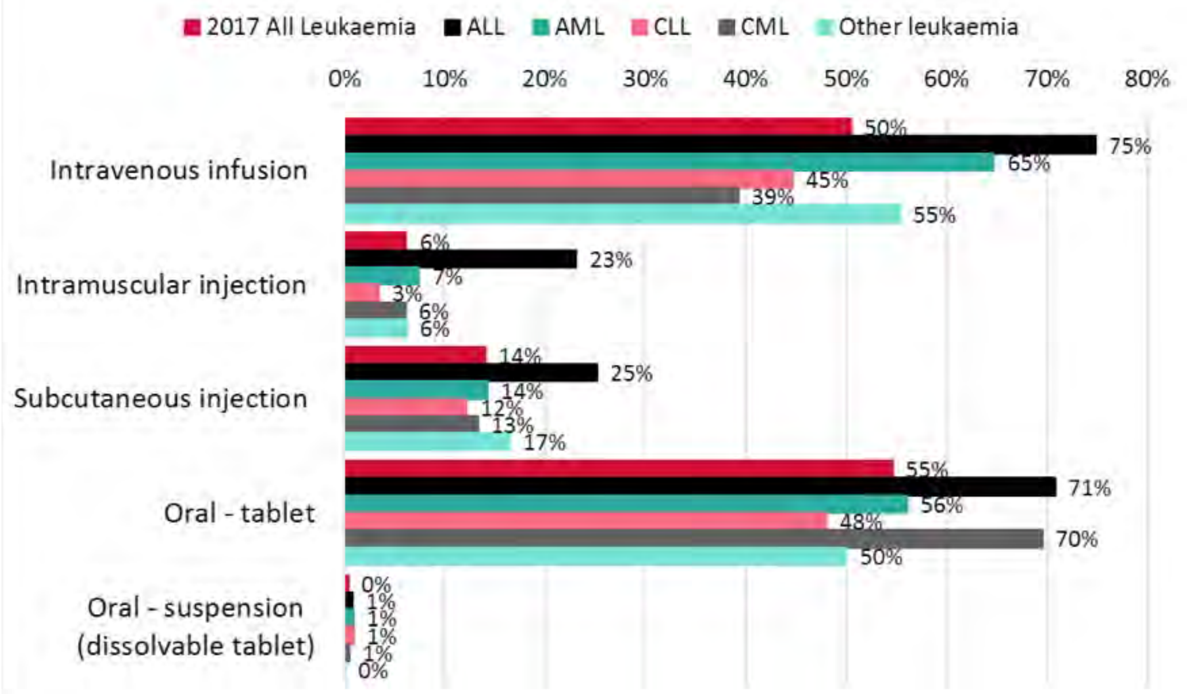


Figure 44: *Treatment method - by leukaemia type*

4.4.11 Impact of treatment on symptoms

There has been little change from the 2016 survey for respondents reporting a significant or complete improvement of their symptoms following their most recent/current treatment (78% - 2017, 76% - 2016).

Once again, CML respondents were less likely to say that there had been an improvement with their symptoms whilst on ongoing treatment.

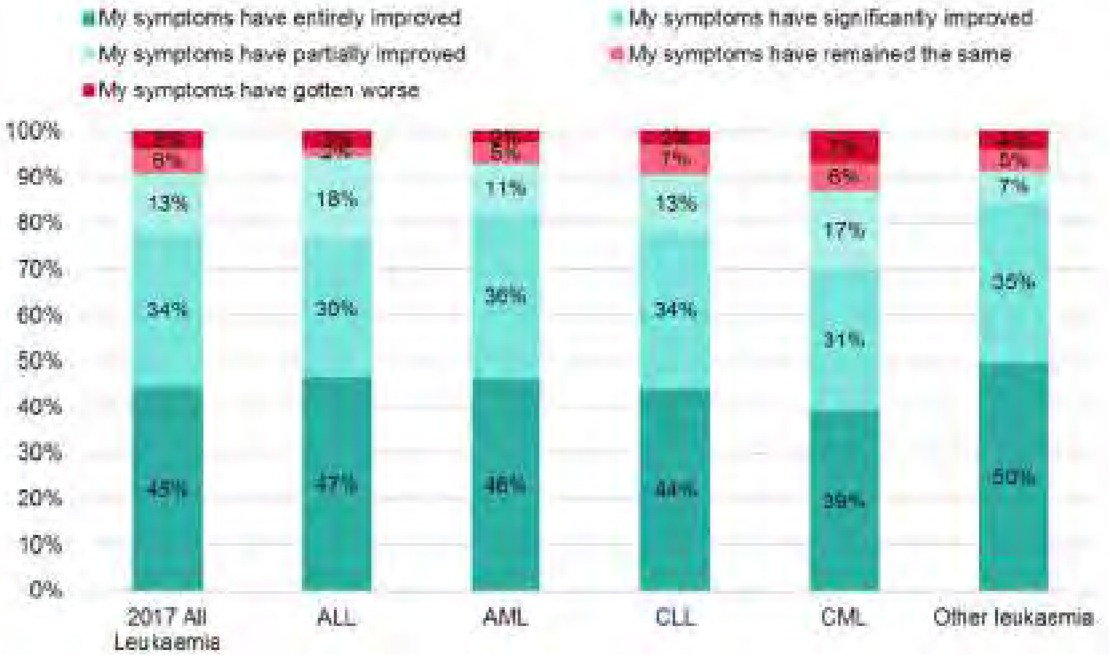


Figure 45: *Impact of treatment on symptoms - by leukaemia type*

4.4.12 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 57% of people saying they had experienced this, 34% had experienced constipation or diarrhoea, and 30% said they experienced muscle, bone or joint pain. Just 7% said they did not have any side effects.

The following side effects were particularly prevalent for some types of leukaemia:

- Infections - experienced by 52% of ALL and 41% AML
- Muscle bone or joint pain - experienced by 44% of CML
- Nausea or vomiting - experienced by 47% of ALL and 34% of AML
- Hair loss - experienced by 46% of AML

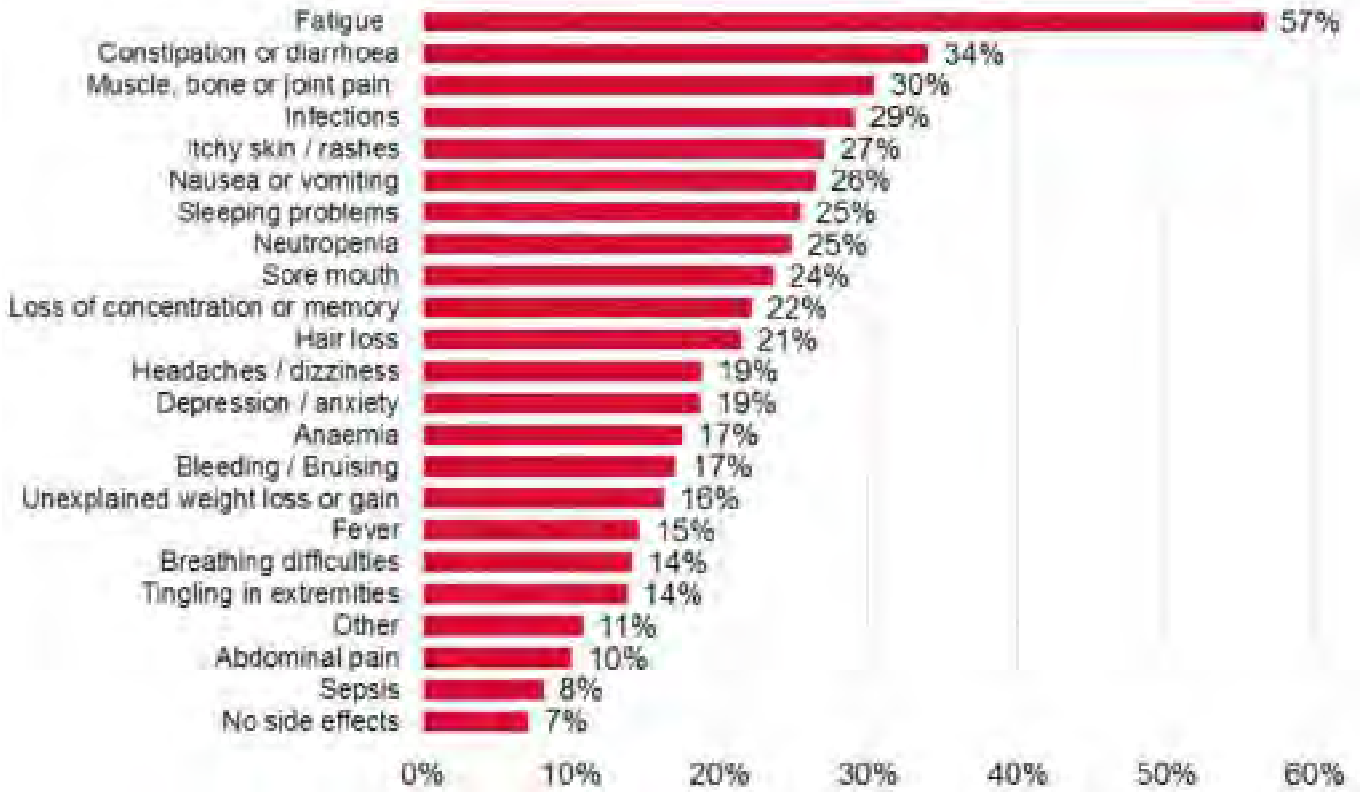


Figure 46: *Impact of treatment on symptoms*

Acute leukaemia patients continue to report that the side effects of their treatment have more of a negative impact than chronic patients. Acute patients were significantly more likely to report that their side effects had a large impact, compared to those with a chronic leukaemia.

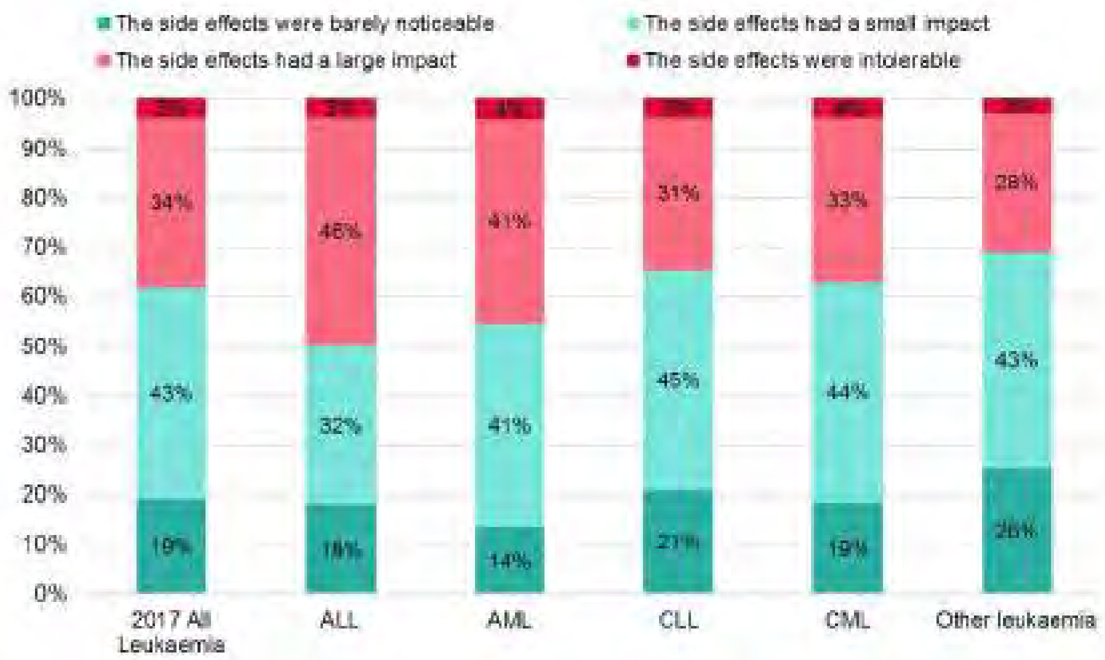


Figure 47: *Impact of side effects - by leukaemia type*

4.4.13 Clinical trials

Looking at the offer of clinical trials by year of diagnosis, there appears to be a decline in patients being offered an option, both in acute and chronic types. However, patients with acute leukaemia continue to be more likely to have been given the option to participate.

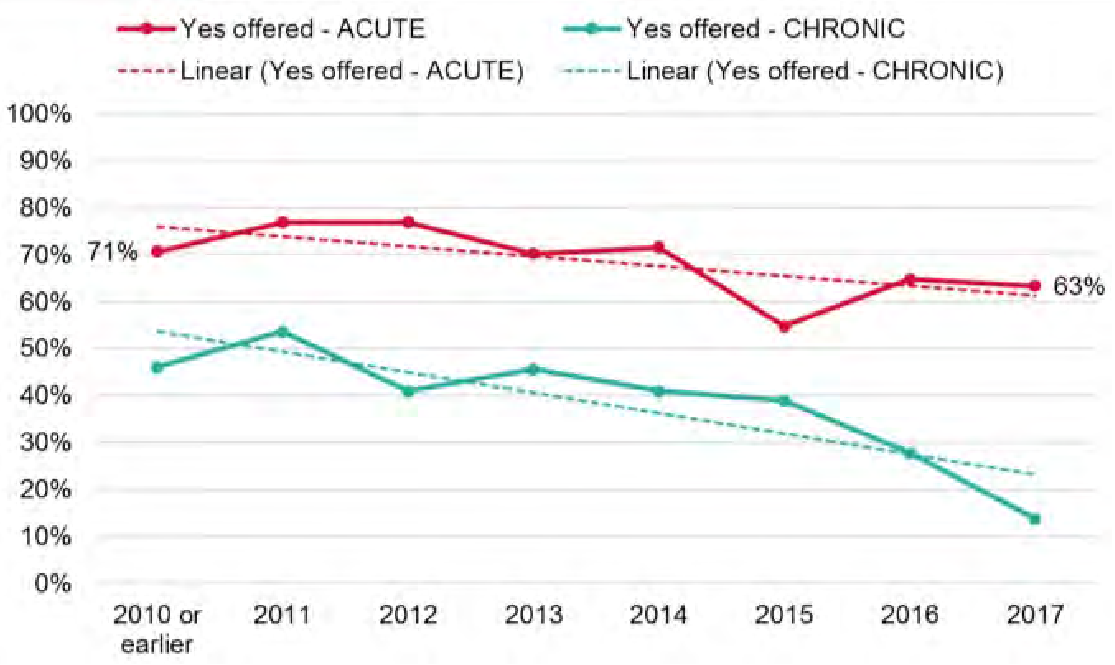


Figure 48: *Given option to participate in clinical trial - by acute and chronic leukaemias*

Overall, of those who were offered the opportunity to join a trial, 79% went on to participate (82% in the 2016 survey). This indicates 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.

Leukaemia Care provides a guide to clinical trials as part of their Know Your Rights Toolkit: Clinical trials – the basics https://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/clinical-trials.pdf

Clinical trials - age breakdown

As in the 2016 survey, this year's results also show that the frequency of patients being given the option to participate in a clinical trial decreases as respondents get older. However, whilst older patients were less likely to be offered the opportunity to participate in a clinical trial, they were as likely to join the trial when offered. It is interesting to note that once again 16-24 group were the least likely to participate in a clinical trial.

Further detail of these and other differences of patient experiences by age can be found 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

4.5 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.

4.5.1 Symptoms since diagnosis

We asked what symptoms respondents had experienced since their diagnosis.

The most frequently experienced symptom was fatigue 67%, followed by feeling weak or breathless 39%, and then sleeping problems and pain in bones or joints, both 33%. 14% of respondents encountered no symptoms post-diagnosis.

Once again, nearly all symptoms were reported more post diagnosis. This could be due to the leukaemia having progressed, or that some of the ailments were 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:

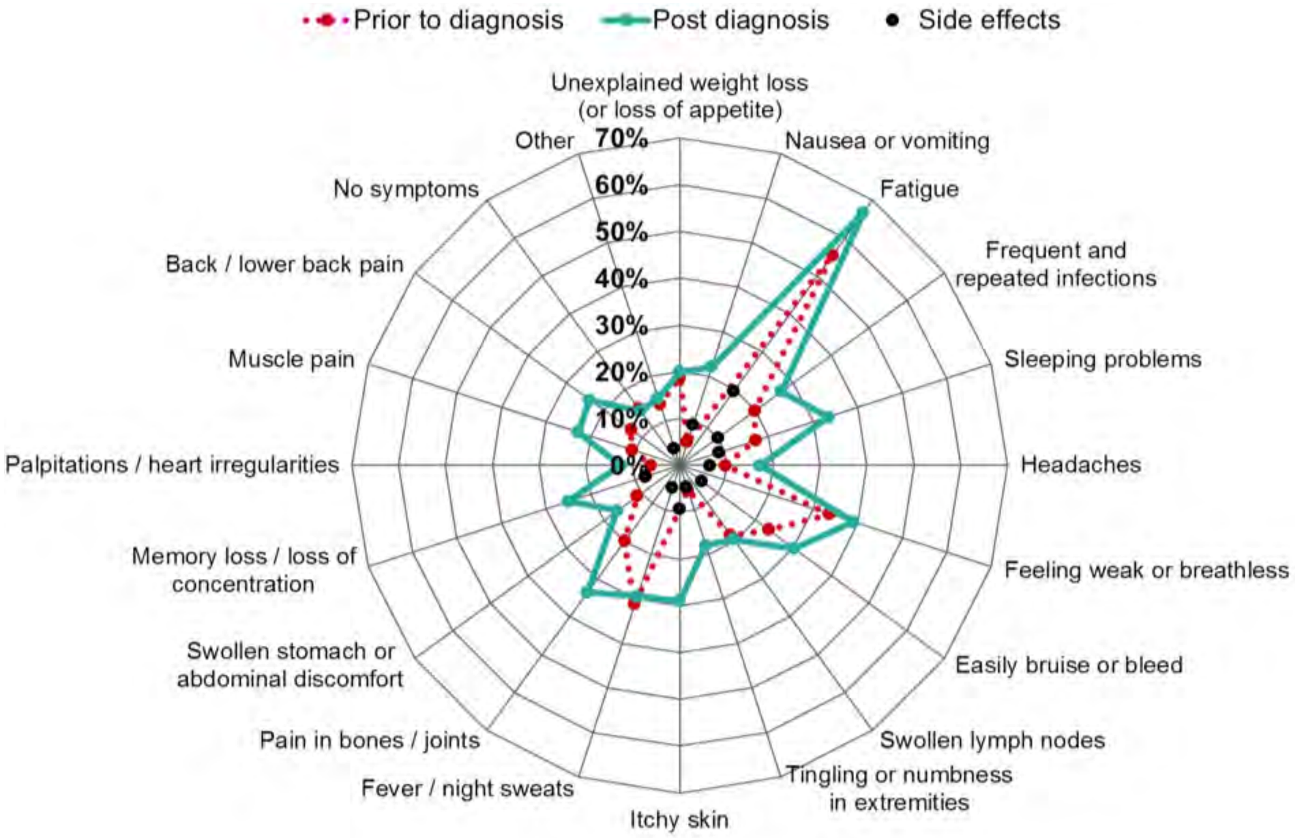


Figure 49: *Symptoms reported prior to diagnosis vs symptoms reported since diagnosis*

4.5.2 Pain and discomfort

Just under half of respondents (49%) experience pain due to their condition, 16% reported experiencing pain regularly and 5% constantly.

There was a difference between the experiences of the cohorts on this question. Patients recruited through charities (Arms 2 and 3) were significantly more likely to report experiencing pain, 53% in Arm 2 and 57% in Arm 3 compared to 43% of Arm 1. This implies that those experiencing pain and discomfort are more likely to reach out to charities for support.

CML respondents continue to report experiencing pain most frequently, followed by those with ALL, as the chart below shows.

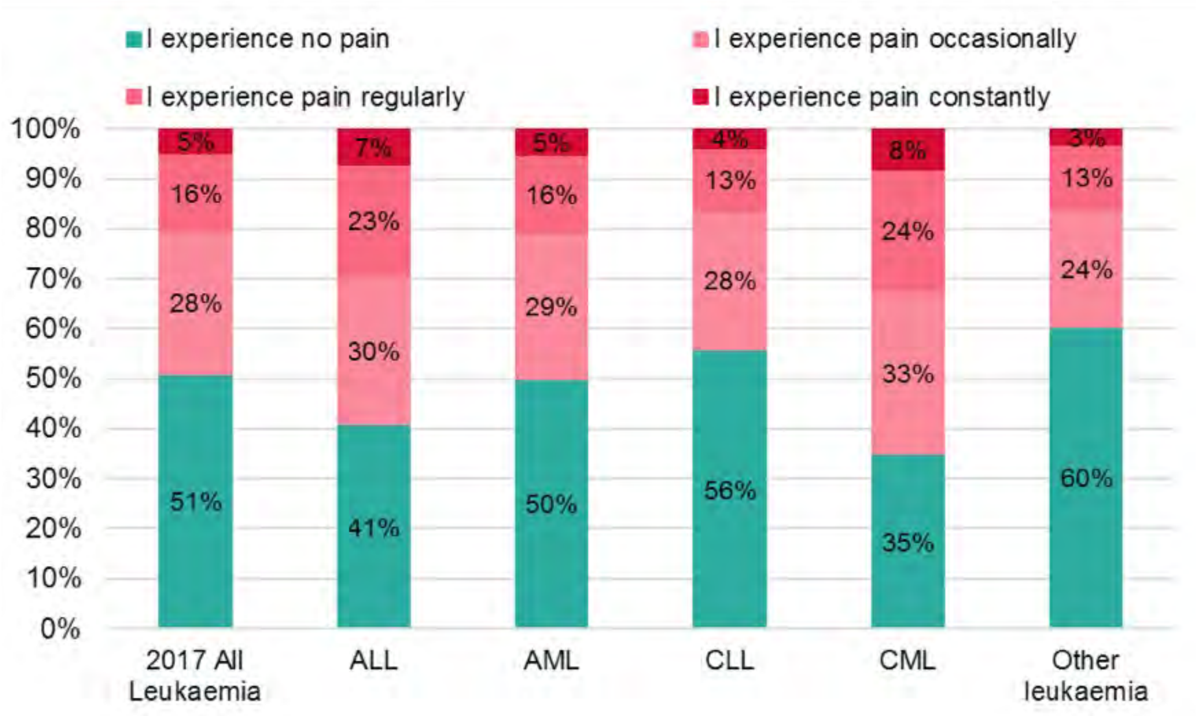


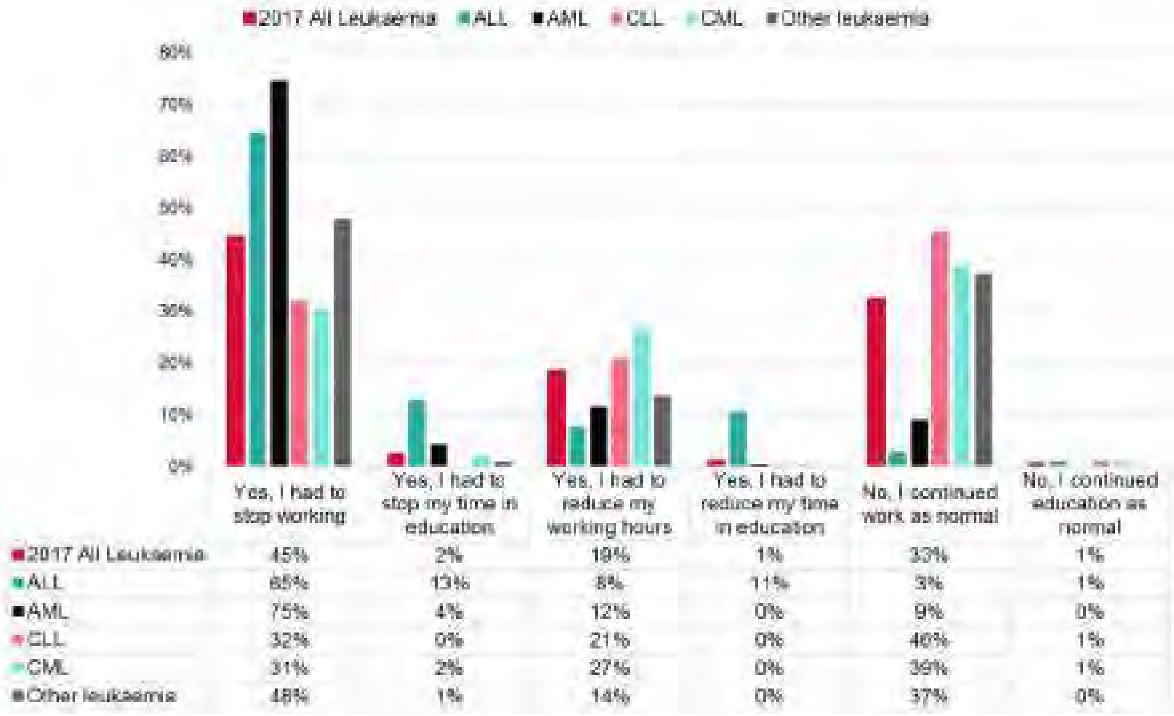
Figure 50: *Frequency of pain experienced since diagnosis - by leukaemia type*

4.5.3 Impact of cancer on work/education

We asked respondents if their 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, 67% reported that their diagnosis had an impact on this, 47% of respondents said they had to stop working or their time in education, and 20% had to reduce their time in work or education. Just over a third (34%) were able to continue as normal.

Respondents with ALL and AML were more likely to experience an impact on work/education; 93% of acute leukaemia patients had to stop or reduce their time in work or education, compared to 56% of chronic patients.



	Yes, I had to stop working	Yes, I had to stop my time in education	Yes, I had to reduce my working hours	Yes, I had to reduce my time in education	No, I continued work as normal	No, I continued education as normal
■2017 All Leukaemia	45%	2%	19%	1%	33%	1%
■ALL	65%	13%	8%	11%	3%	1%
■AML	75%	4%	12%	0%	9%	0%
■CLL	32%	0%	21%	0%	46%	1%
■CML	31%	2%	27%	0%	39%	1%
■Other leukaemia	48%	1%	14%	0%	37%	0%

Figure 51: *Impact of leukaemia on work/education - by leukaemia type*

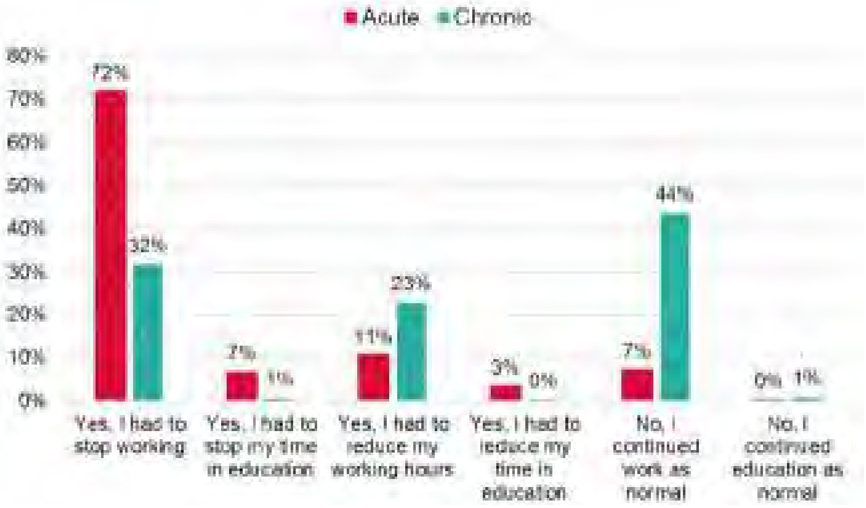


Figure 52: *Impact of leukaemia on work/education - by acute and chronic leukaemia*

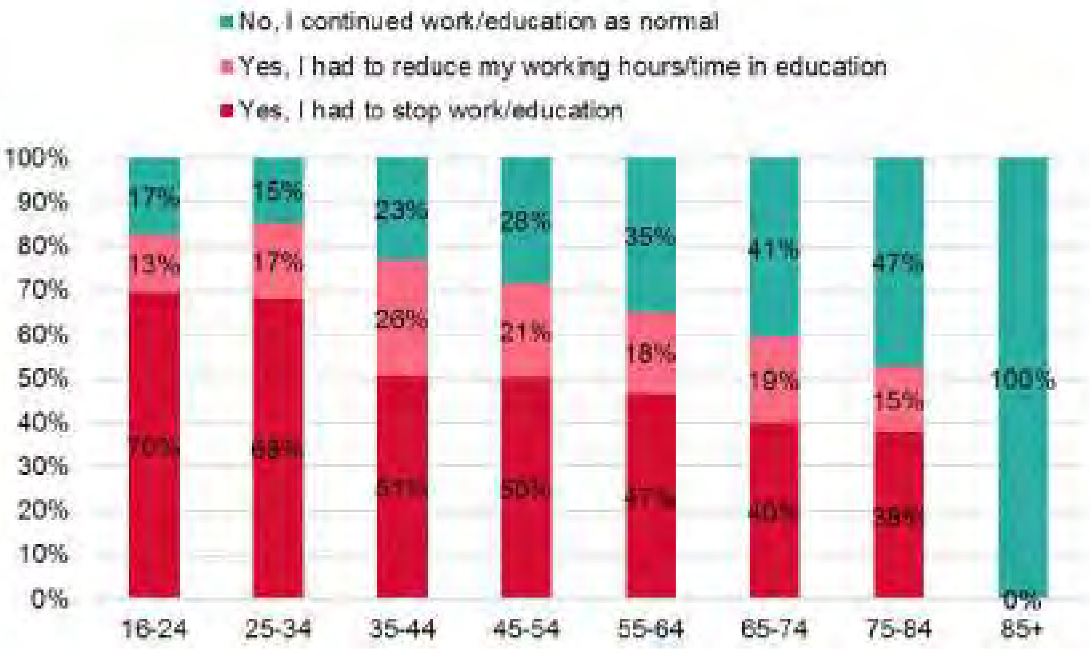


Figure 53: *Impact of leukaemia on work/education - by age group*

We looked to understand more about the impact of a leukaemia diagnosis on a patient's work life or education by asking respondents if the long-term impact was permanent or temporary. There were clear differences between leukaemia types, with chronic patients significantly more likely to say the impact was permanent (56%), compared to those with an acute leukaemia (34%).

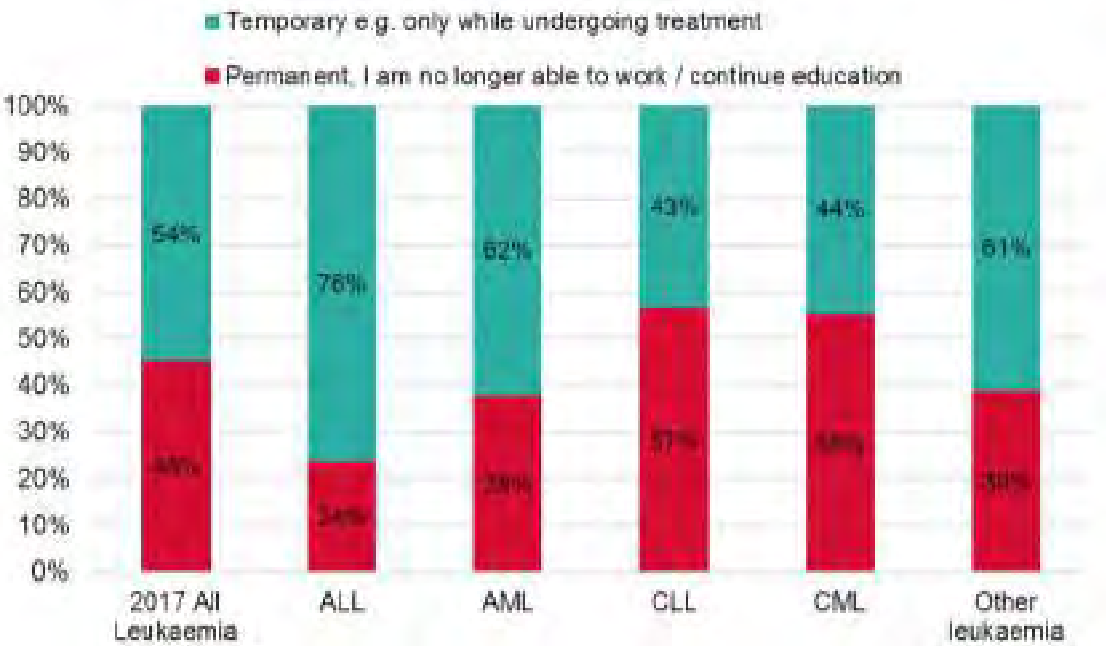


Figure 54: *Duration of impact of leukaemia on work/education - by leukaemia type*

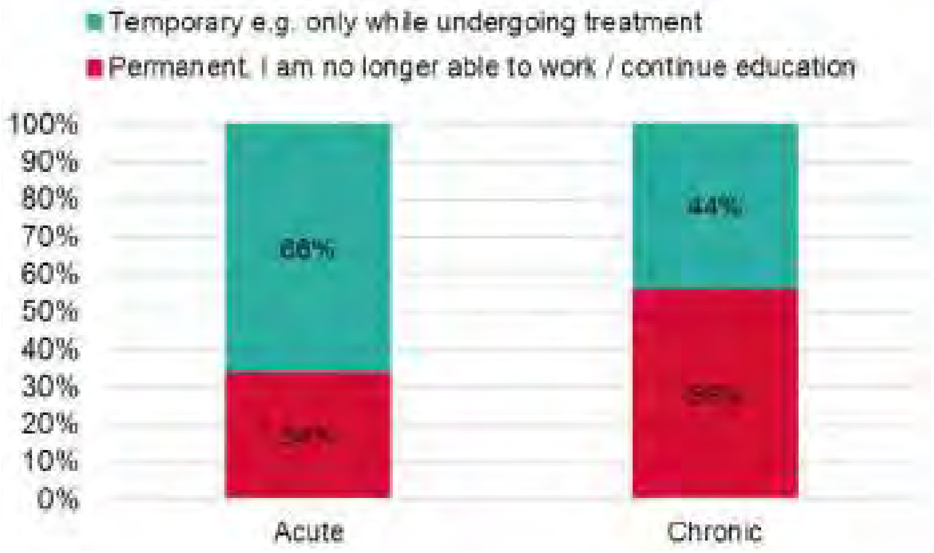


Figure 55: *Duration of impact of leukaemia on work/education - by acute and chronic leukaemia*

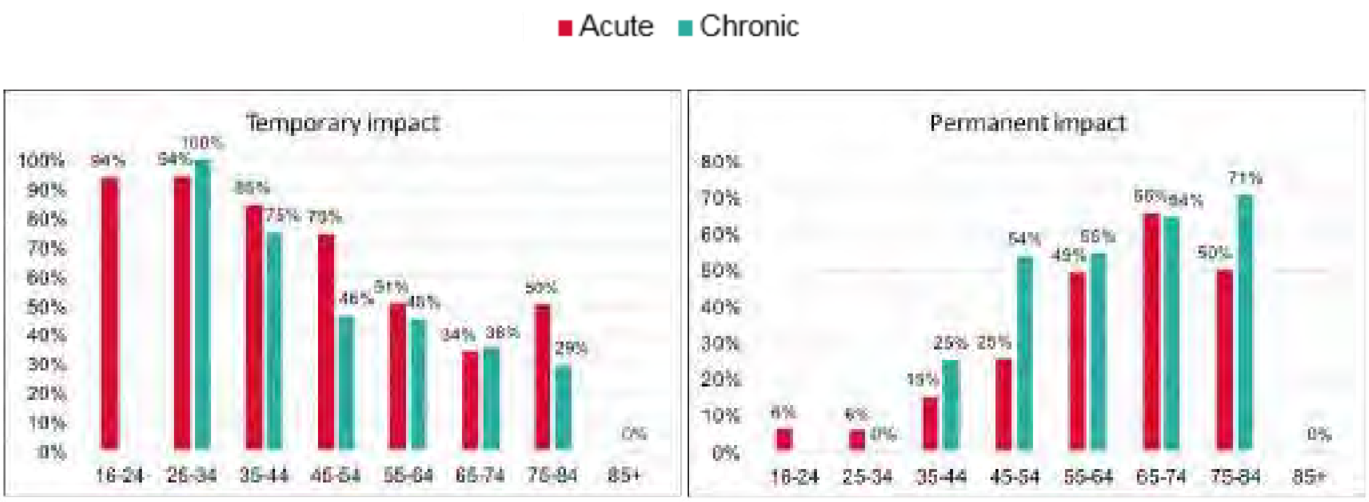


Figure 56: *Duration of impact of leukaemia on work/education - by age group*

Leukaemia Care provides advice and guidance about employment in their Know Your Rights Toolkit: Employment rights 1: Being/becoming employed https://www.leukaemiacare.org.uk/wp-content/uploads/Employment-Rights-BeingBecoming-Employed-Online-version.pdf

4.5.4 Impact of cancer on finances

We asked respondents what financial impact their cancer had on them. 52% said they hadn't experienced any impact and 5% reported a positive impact, possibly due to reasons such as insurance pay-outs. However, 43% of people who responded to this question reported a negative financial impact.

Acute leukaemia patients continue to be more likely to report 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.

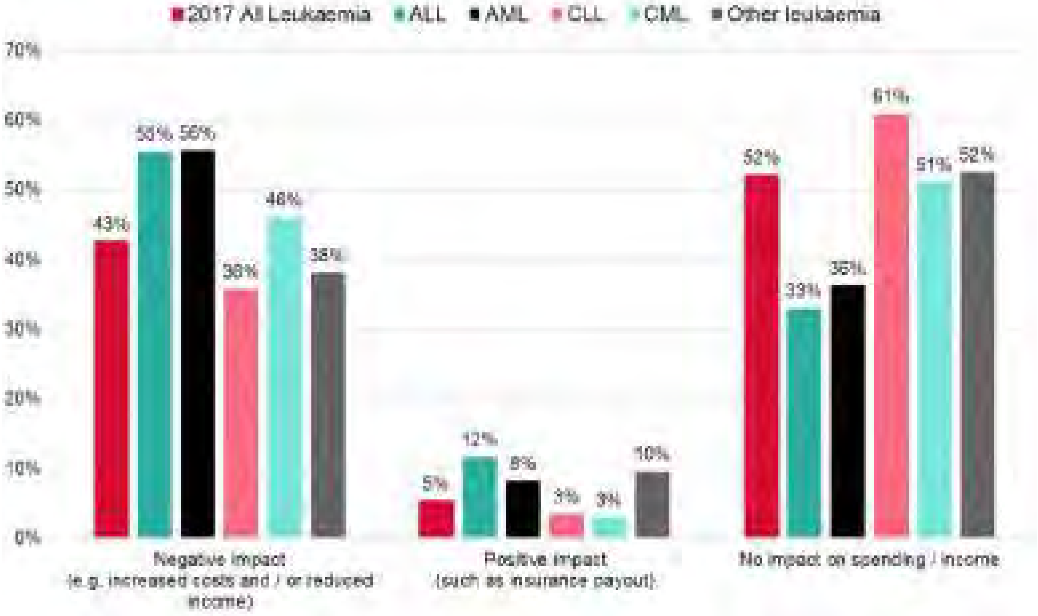


Figure 57: *Impact of leukaemia on finances - by leukaemia type*

Of those respondents who said they experienced a negative financial impact, 64% said that their monthly costs had increased - over a third (35%) of these respondents reported a monthly increase of over £250. This varies between leukaemia types from 44% ALL, to 29% CLL, as the chart below demonstrates.

Figure 58: *Monthly cost impact of leukaemia - by leukaemia type*

In addition, we also asked the respondents who said they experienced a negative financial impact, if they had experienced a reduction in their income. The chart below illustrates the reduction in income reported by those patients who said they had reduced their working hours or stopped working.

Figure 59: *Monthly cost impact of leukaemia - by working status*

Treatment and costs analysis

Patients who have been on ‘watch and wait’ are significantly more likely to report a permanent impact on their ability to work or complete education compared to those who started treatment straight away (58% ‘watch and wait’, 41% started straight away) and significantly less likely to say the impact was temporary (42% ‘watch and wait’, 59% started straight away).

However, patients who started treatment straight away reported a bigger impact on reduction of income and increase in costs compared to those who were on ‘watch and wait’.

One of the questions in the 2016 CPES asked if hospital staff gave information about how to get financial help or benefits they might be entitled to. Only 61% of leukaemia patients who would have liked this type of information were given it. Given the number of leukaemia respondents reporting a negative impact (both permanent and temporary), it is important that they are signposted to places they can find and access help.

4.5.5 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. Just under a third (31%) 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 similar impact on both acute and chronic respondents.

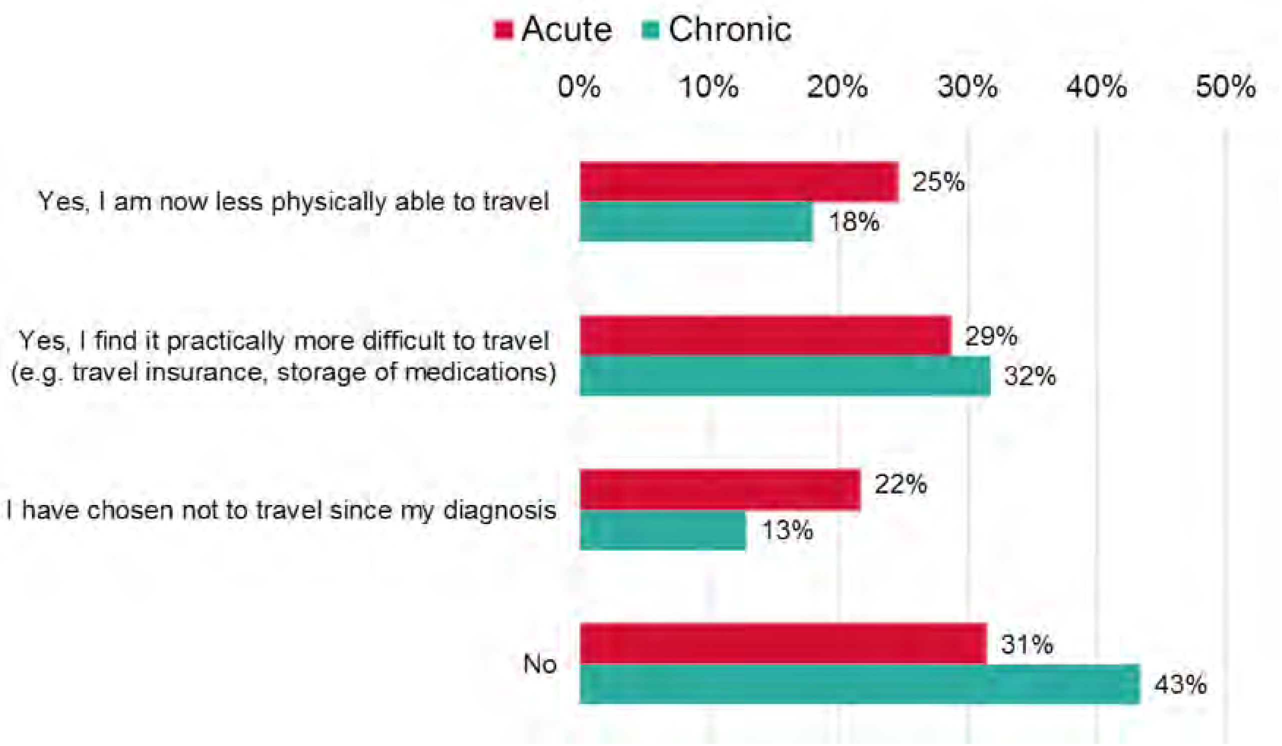


Figure 60: *Impact of leukaemia on travel - by acute and chronic leukaemia*

4.5.6 Impact of cancer on emotional well-being

We asked respondents how their emotional well-being had changed since their diagnosis. Some key findings are listed below:

Leukaemia type analysis

- CLL respondents reported the least change (60%) while ALL reported most change (85%)
- AML and those within the ‘Other leukaemia’ category reported feeling more positive than other leukaemia types (28% AML, 33% ‘Other leukaemia’
- ALL, AML and CML reported the most negative change (ALL 64%, AML 47%, and CML 47%)
- ALL were more likely to feel constantly depressed or anxious (7%)

Patient cohort analysis

- Respondents from Arms 2 and 3 were less likely to experience no change in their emotional well-being - 30% Arm 2, 26% Arm 3 compared to 36% Arm 1
- Respondents from Arms 2 and 3 were more likely to report feeling depressed or anxious more often since their diagnosis - 46% Arm 2, 58% Arm 3 compared to 37% Arm 1
- Respondents from Arm 3 were significantly less likely to feel more positive than Arms 1 and 2 – 16% Arm 3, compared to 26% Arm 1, and 24% Arm 2
- Respondents from Arm 3 were significantly more likely to feel constantly depressed or anxious than Arms 1 and 2 – 7% Arm 3, compared to 3% Arm 1, and 4% Arm 2

Living situation analysis[2]

- Respondents with dependent children were significantly less likely to report feeling more positive since their diagnosis than those without – 16%, compared to 25%
- Respondents with dependent children were significantly more likely to report feeling depressed or anxious more often since their diagnosis than those without - 52%, compared to 37%
- Respondents with dependent children were significantly more likely to report feeling depressed or anxious constantly since their diagnosis than those without - 8%, compared to 4%

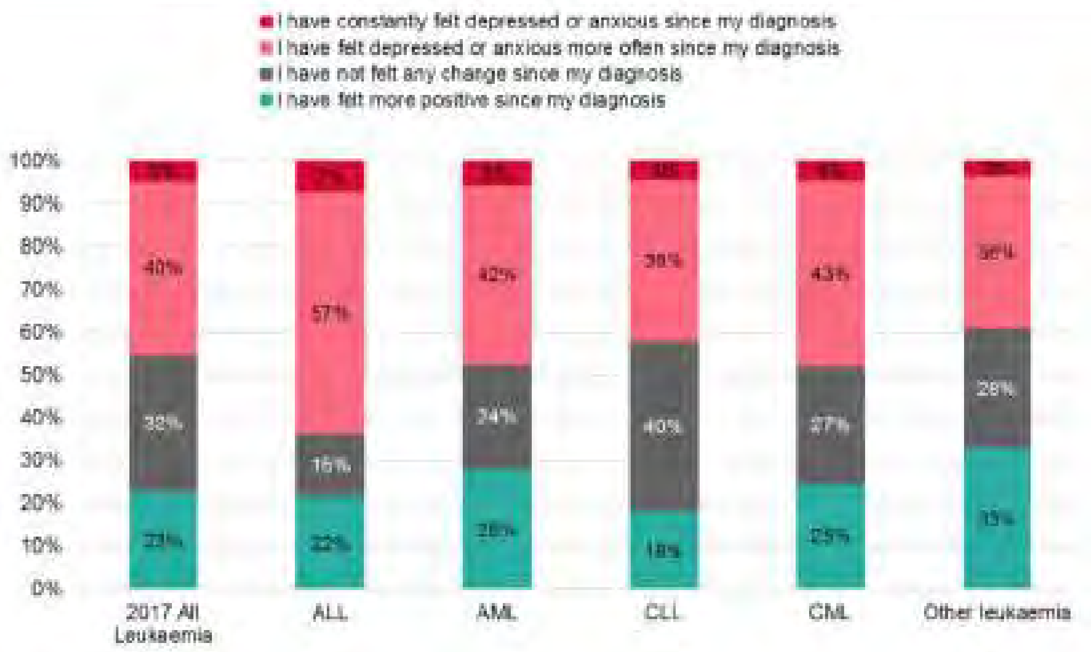


Figure 61: *Impact of leukaemia on emotional well-being - by leukaemia type*

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[2] Excludes the 17 respondents who stated ‘other’.

Patients reporting a negative change in their emotional wellbeing is an ongoing issue as shown by the chart below.

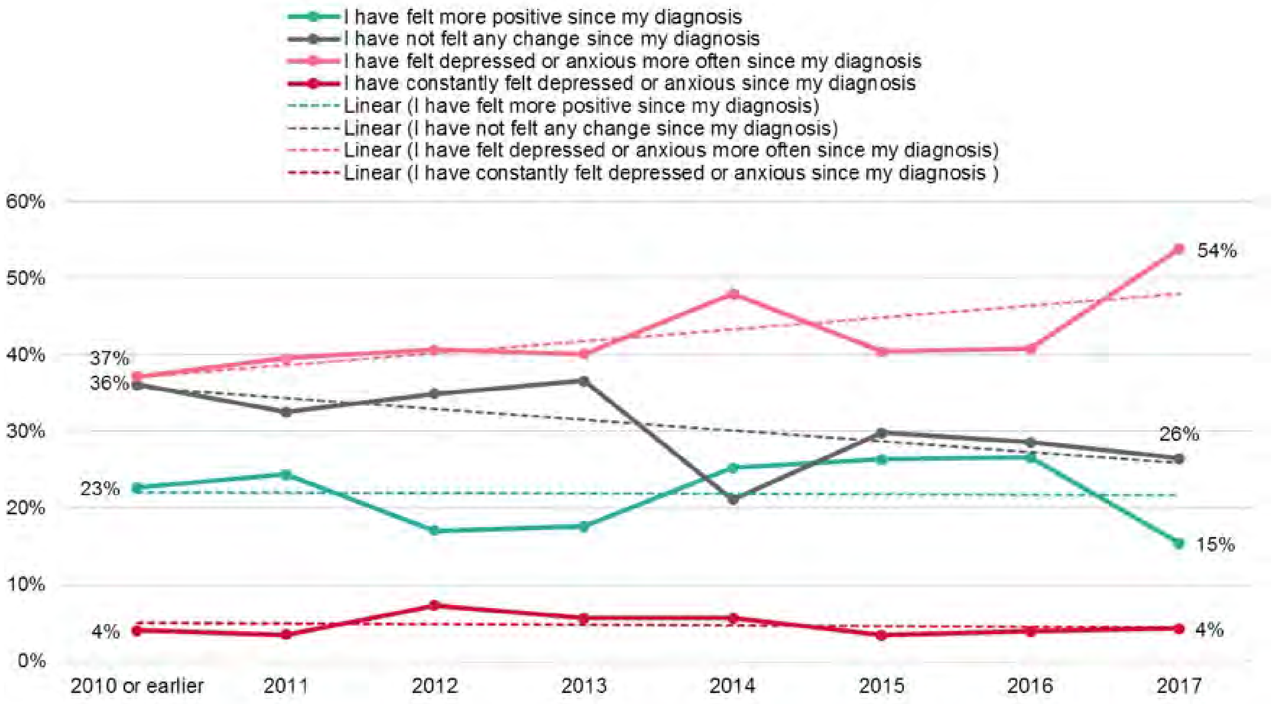

Figure 62: *Impact of leukaemia on emotional well-being - by year of diagnosis*

Depression and anxiety are often referenced together, despite being separate conditions, because many people with anxiety also develop depression and vice versa. We asked those people who reported feeling more depressed/anxious since their diagnosis if they felt only depressed, only anxious, or if they did indeed feel both depressed AND anxious. The majority of respondents reported feeling either both depressed and anxious (51%) or just anxious (40%); just 9% said they only felt depressed.

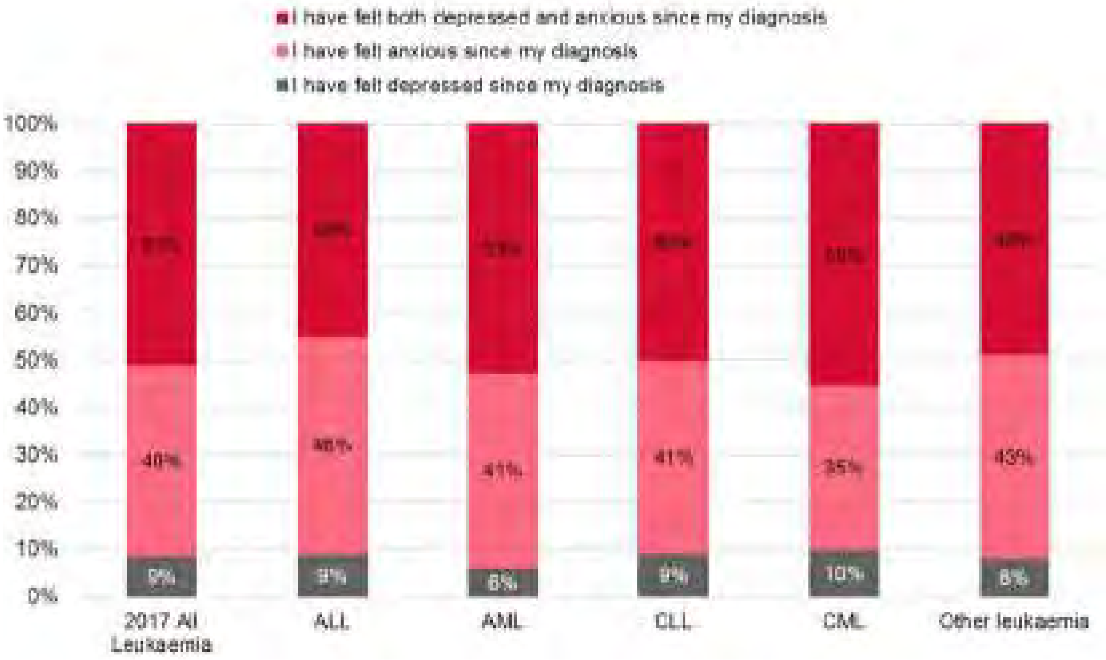

Figure 63: *Type of emotional impact - by leukaemia type*

Impact of cancer on emotional well-being – ‘Watch and wait’ breakdown

Respondents who started treatment straight away were significantly more likely to report feeling more positive since their diagnosis, or experience no change in their emotional well-being, than CLL respondents who were on ‘watch and wait’ at some point in their treatment journey.

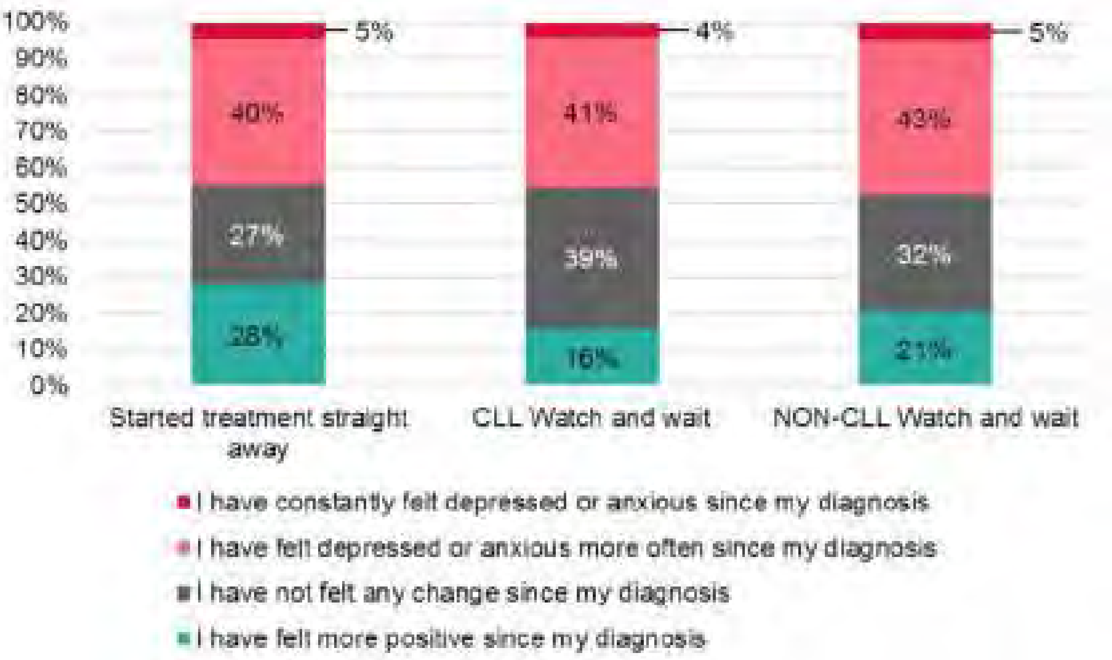

Figure 64: *Impact of leukaemia on emotional well-being – by started treatment and ‘watch and wait’*

In addition, those respondents who are still on ‘watch and wait’ (the majority of which are CLL patients) are significantly more likely to report feeling depressed or anxious more often, or constantly, than those ‘watch and wait’ respondents who have now started treatment.

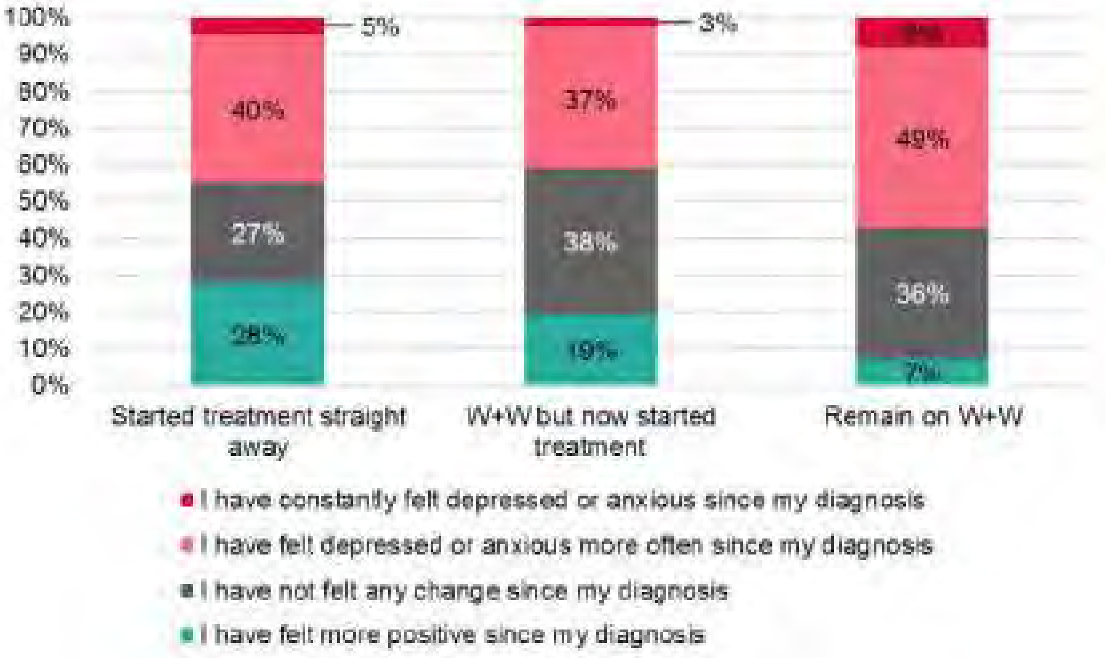

Figure 65: *Impact of leukaemia on emotional well-being – by journey to starting treatment*

4.6 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.

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

Initially respondents were asked if hospital staff gave them information for people with blood cancer, and then for those that said they were, we then asked what information they were given.

The majority (96%) of respondents did want information, and of these 92% said they were given information of some description. This ranged from 90% in CLL to 96% in ALL.

Once again there was a significant difference between the cohorts, 96% of Arm 1 were given information compared to 89% in Arm 2 and 86% in Arm 3. This may be a reason these patient cohorts instead reach out to charities for information and support.

Respondents who were not given any information were significantly more likely to report feeling depressed or anxious more often or constantly since their diagnosis.

Respondents were able to select multiple answer options to say what information they had been given. Overall, patients were most likely to say they had been given information about their blood cancer and least likely to say they had been given information on emotional support.

CLL and CML were significantly less likely to report being given emotional and practical information. This indicates unmet needs for patients living with these conditions, especially as they may not regularly visit hospitals as part of their treatment.

The charts below show the range of answers for the different types of leukaemia.

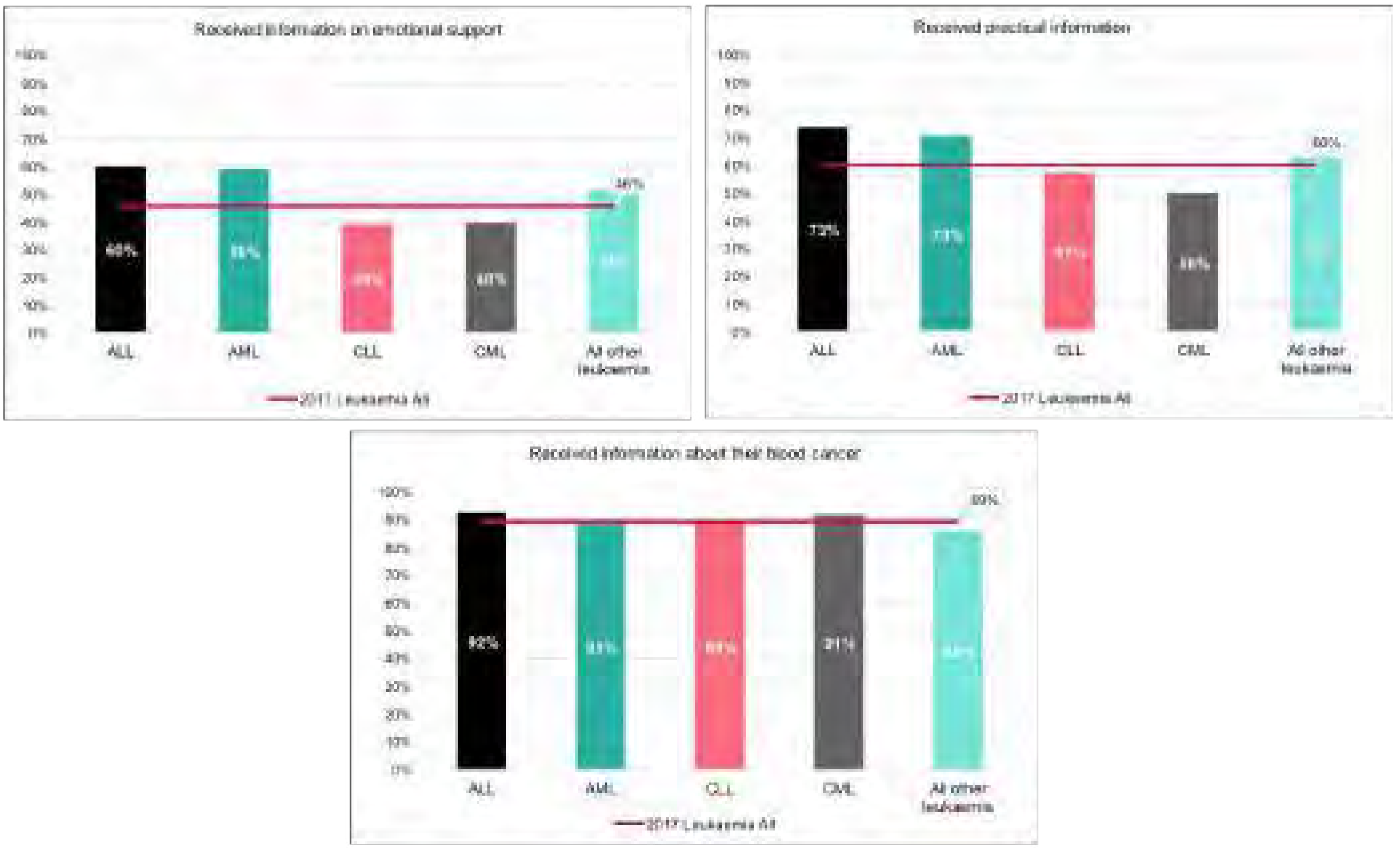

Figure 66: *Type of information given – by leukaemia type*

A bigger proportion of respondents who said they have felt more positive since their diagnosis, said they had been given information on emotional support; 53% compared to 45% who reported a negative change, and 40% who said they felt no change.

We then asked in what form respondents received this information. Whilst most patients said they were given both verbal and written information, there was variation between leukaemia types. Chronic patients were less likely to be given both verbal and written information (64%) compared to acute patients (77%).

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

As in 2016, 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 continue to be more likely to be given information on support at diagnosis, and those with an acute leukaemia more likely to get information during and after treatment, and throughout their cancer journey.

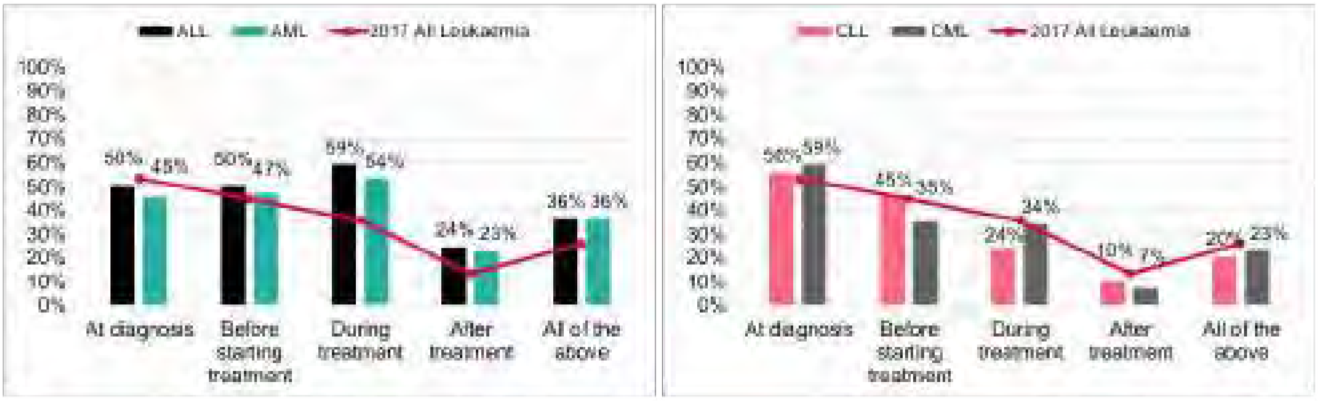

Figure 67: *When information was provided - by acute and chronic leukaemia*

On the whole, respondents felt that the information they were given was consistent, and of these 57% felt that the information was easy to understand and they understood all of it.

Between the leukaemia types, respondents with AML were most likely to say the information they were given was difficult to understand and they did not understand most of it (8%).

There was little difference between how the information was delivered, and ease of understanding.

4.6.2 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 the most common responses were that the health professional didn't recommend anything, or they were told to come back to the hospital, both 28%. 15% were recommended to contact Leukaemia Care and 18% were recommended to another organisation.

Respondents from Arms 2 and 3 cohort were more likely to say that their health professional did not recommend anything compared to Arm 1 (23% Arm 1, 30% Arm 2 and 38% Arm 3).

Respondents with AML and Other leukaemia were least likely to say their health professional did not recommended anything (23%) with the other types ranging between 24%- 31%.

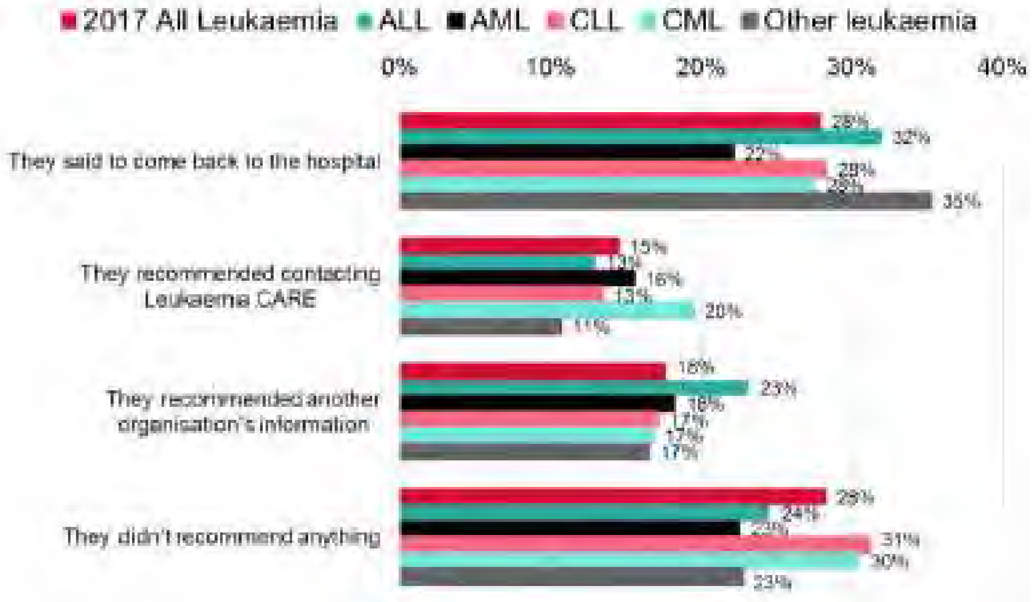

Figure 68: *Recommendation of finding further information - by leukaemia type*

4.6.3 Information from the Internet

As in the 2016 survey, we asked respondents if their health professional made any reference to online information or the Internet. Most people (69%) continue to say no, their health professional didn't say anything about the Internet (67% in the 2016 survey). 11% were told not to look at the Internet and not to trust online information, and 20% were told to look online but only at trusted websites.

However, further analysis of this question by year of diagnosis indicates a significant increase in the percentage of patients being told to look online at trusted websites and a decrease in patients not being told anything about the Internet.

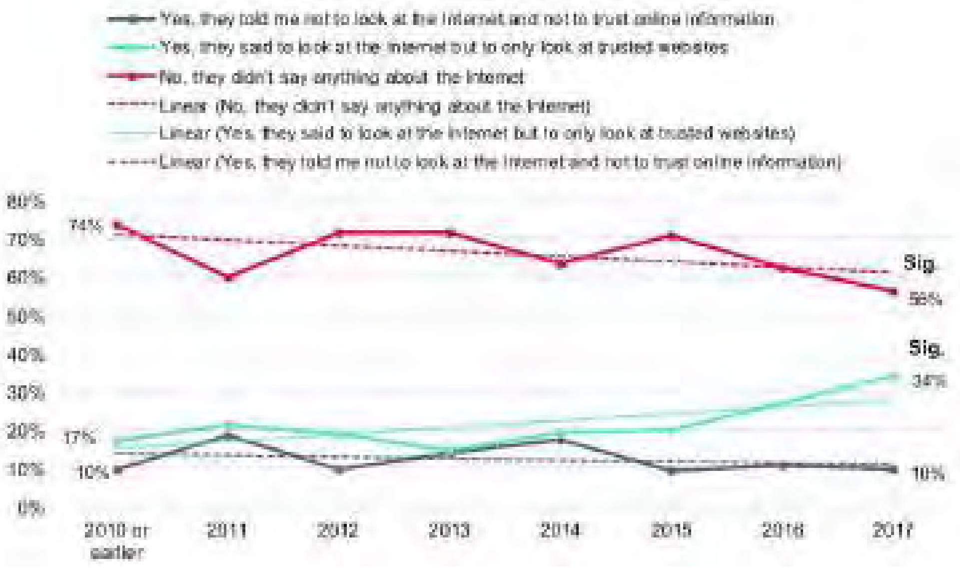

Figure 69: *Recommendation of using the Internet – by year of diagnosis*

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, 84% found it useful, 9% did not find it useful and 7% thought the information was inaccurate or out of date. In addition, those with a more recent diagnosis are more likely to report finding the information useful.

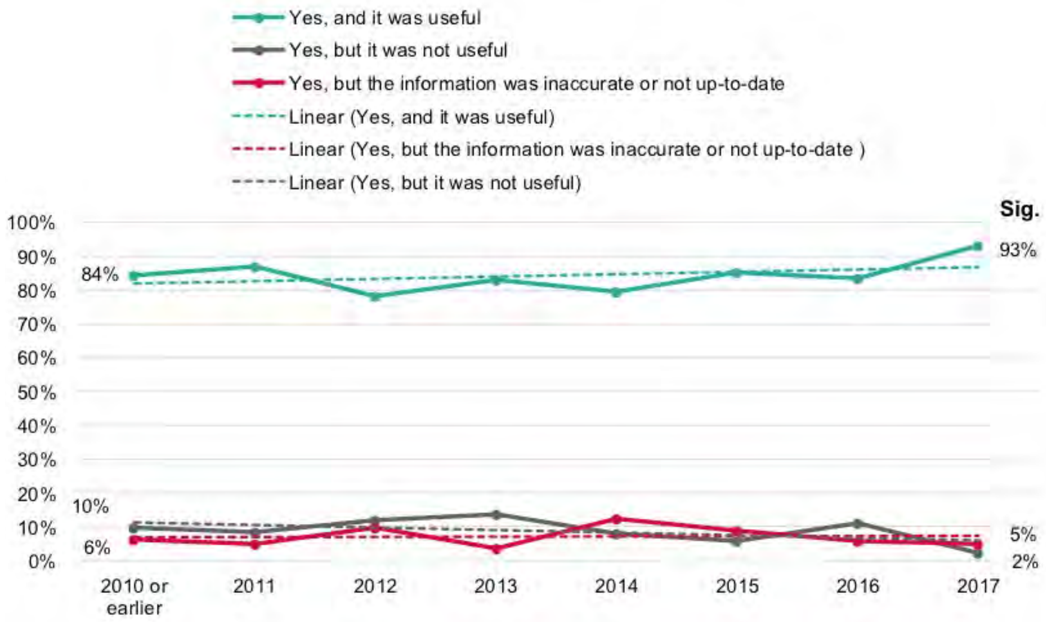

Figure 70: *Usefulness of Internet information – by year of diagnosis*

Of the respondents who said their health professional didn't say anything about the Internet, 57% reported they went on to use it. In addition, 55% of respondents said they used the Internet, despite their health professional telling them not to look at it.

As in 2016, we looked at the relationship between advice given by health professionals, and how useful respondents found online information to be. Respondents whose health professional told them to look at trusted websites were significantly more likely to find useful information; this supports our 2016 findings.

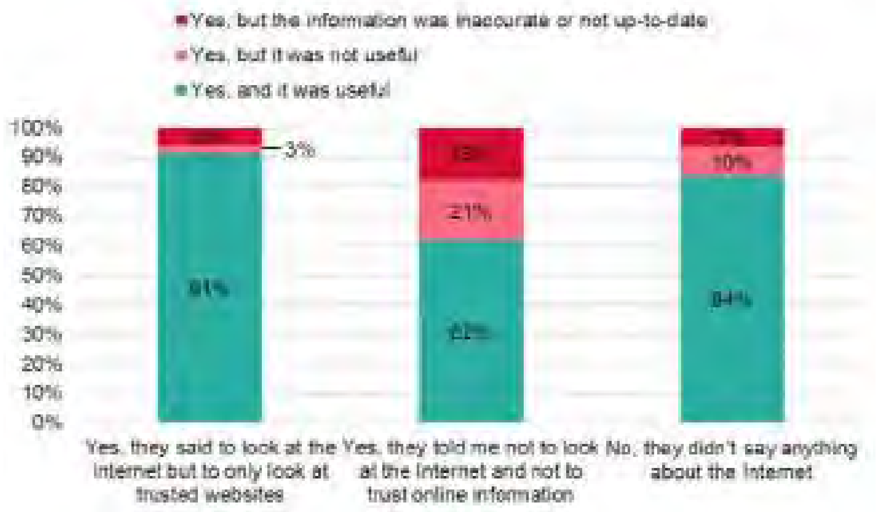

Figure 71: *Usefulness of Internet information - by advice given from health professional*

Leukaemia Care provides a guide finding good information on the Internet as part of their Know Your Rights Toolkit: Using the Internet to find information https://www.leukaemiacare.org.uk/wp-content/uploads/2018/02/clinical-trials.pdf

4.6.4 Additional areas/types of support

It is important to understand if respondents are 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 continues to be distinct variation in the experiences reported between the different leukaemia types. Acute leukaemia patients are more likely to be offered additional support than those with a chronic leukaemia. ALL respondents were more likely to be offered support across all areas apart from Online Forums, and CLL patients were least likely to be offered support across all areas apart from Online Forums.

Overall, 31% of respondents said they had not been offered additional support, however around a fifth of acute patients said this (18%/20%) compared to 37% and 30% of those with a chronic leukaemia.

	I was not offered additional support	Other	Online forums	Support groups	Access to a Clinical Nurse Specialist (CNS)	Counselling or psychotherapy	Buddying or befriending
■ 2017 All Leukaemia	31%	3%	4%	21%	61%	18%	3%
■ ALL	18%	5%	5%	28%	71%	43%	5%
■ AML	20%	2%	2%	27%	71%	35%	3%
■ CLL	37%	2%	4%	15%	56%	8%	2%
■ CML	30%	2%	8%	28%	63%	17%	2%
■ Other leukaemia	28%	5%	2%	22%	63%	17%	3%

Figure 72: *Offered additional support - by leukaemia type*

The chart below illustrates sources of additional support as reported by year of diagnosis. 2017 results should be viewed with the understanding they have a heavy bias from Arm 3.

Overall, the provision of a CNS shows some growth, as does the provision of counselling or psychotherapy. There appears to be a decline for support groups and respondents not being offered additional support.

Figure 73: *Offered additional support - by year of diagnosis*

The charts below illustrate the uptake of additional support and how useful respondents found this. Between 11% and 31% of respondents didn't access the different types of support offered to them. However, where respondents did use the support, the majority reported that it helped them feel better or more positive.

Figure 74: *Accessed additional support*

Watch and wait analysis

There are a number of significant differences between 'watch and wait' respondents and those who started treatment straight away in relation to the offer of additional support.

Compared to respondents who started treatment straight away, respondents who were on 'watch and wait' but have now started treatment were:

- significantly less likely to say they were offered counselling or psychotherapy - 9% compared to 25%
- significantly less likely to say they were offered support groups - 17% compared to 25%
- significantly more likely to say they were not offered additional support - 30%, compared to 26%

Compared to respondents who started treatment straight away, respondents who are still on 'watch and wait' were:

- significantly less likely to say they were offered counselling or psychotherapy - 5% compared to 25%
- significantly less likely to say they were given access to a CNS - 30% compared to 66%
- significantly less likely to say they were offered support groups - 12% compared to 25%
- significantly more likely to say they were not offered additional support - 60% compared to 26%

Compared to respondents who were on 'watch and wait' but have now started treatment, respondents who remain on 'watch and wait' were:

- significantly less likely to say they were offered counselling or psychotherapy - 5% compared to 9%
- significantly less likely to say they were offered access to a CNS - 30% compared to 65%
- significantly less likely to say they were offered support groups - 12% compared to 17%
- significantly more likely to say they were not offered additional support - 60%, compared to 30%

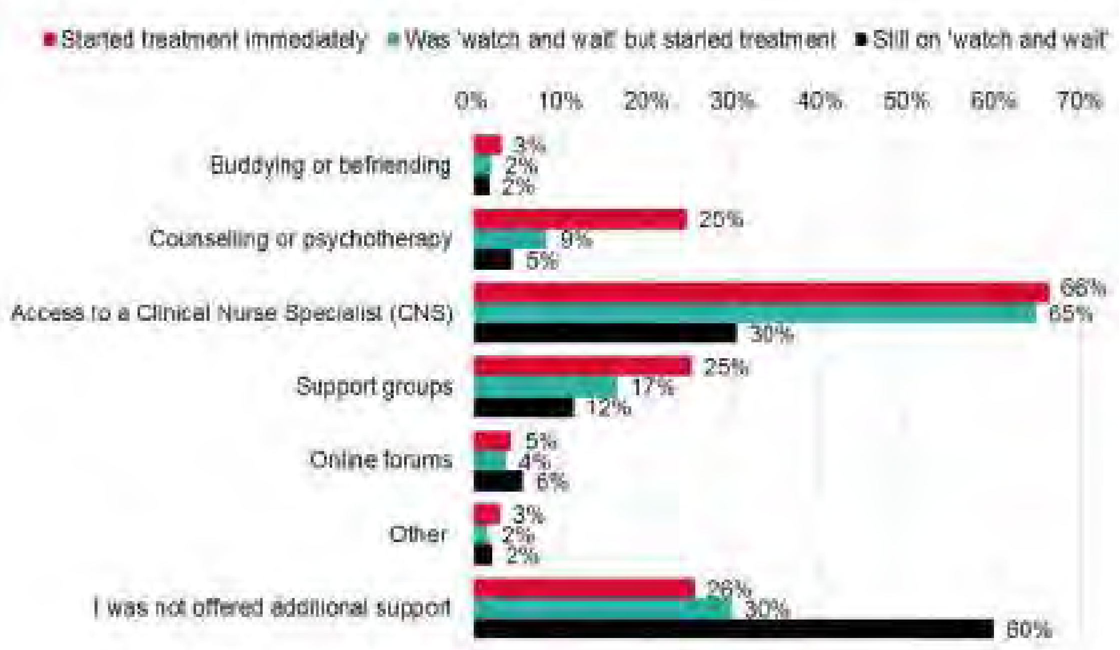

Figure 75: *Offered additional support - by journey to starting treatment*

Clinical Nurse Specialist analysis

Overall, 61% of respondents said they were given access to a CNS[3]. Our results continue to be low in comparison to CPES results: in 2016 CPES, 88% of leukaemia patients who replied said they had been given the name of a CNS who would support them through their care, and 89% said they found it easy to contact their CNS.

There are still clear differences in provision between the leukaemia types: 71% of ALL and AML respondents reported that they were given access to a CNS, compared to 56% CLL and 63% CML.

As previously reported, patients still on 'watch and wait' are significantly less likely to have been given access to a CNS than those who have started treatment.

In the 2017 survey we asked those respondents who said they were given access to a CNS, when they were they given access. We gave a number of time points in the patient journey and allowed respondents to tick all that applied to them. As with the provision of information, respondents predominantly were given access to a CNS during the early stages of their cancer journey and during treatment. Respondents were less likely to say they had access all through their journey and after treatment had ended.

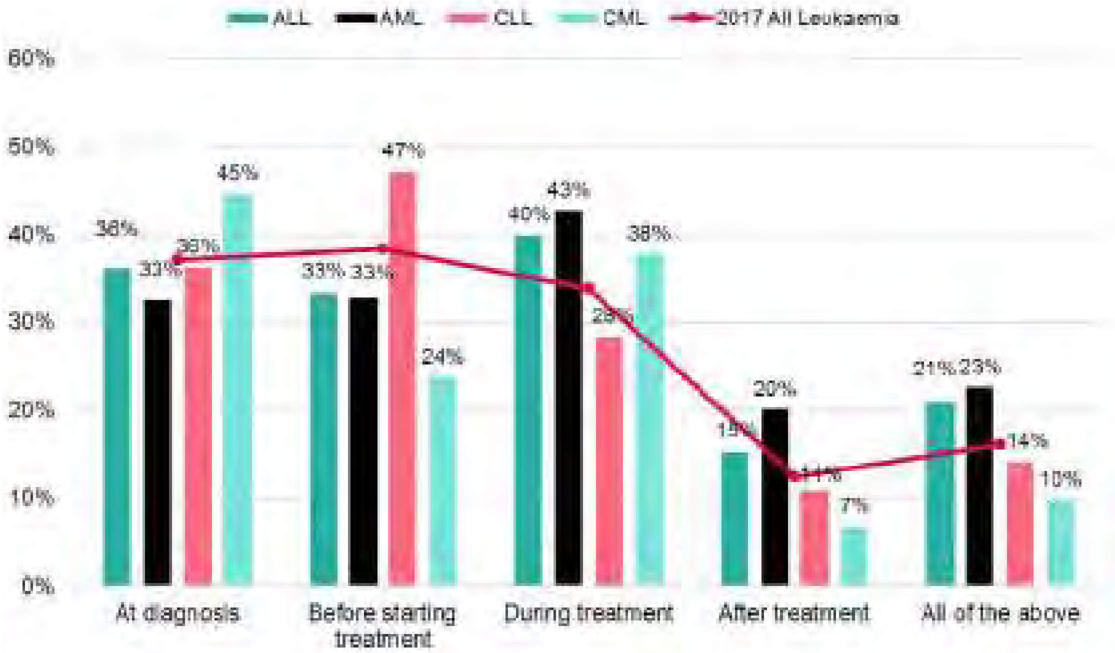

Figure 76: *When offered additional support - by leukaemia type*

It is widely acknowledged that the presence of a CNS is a powerful and positive influence on a cancer patient's experience. Therefore, it is important that this support is made available across all leukaemia types and treatment paths.

To promote the importance of the CNS, Leukaemia Care launched their #myCNSmatters campaign at the end of 2017. This campaign aimed to highlight the improvements a CNS adds to patient experience and say thank you to hundreds of Clinical Nurse Specialists involved in the care of blood cancer patients across the country.

https://www.leukaemiacare.org.uk/wp-content/uploads/2018/03/cnsreport.pdf

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[3] This figure is much higher than the 2016 survey where just 37% of respondents reported being given access to a CNS. This has been analysed further, but other than the question being moved three questions earlier we can see no clear reason why this is the case.

4.6.5 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.

As a whole, respondents reported the two most common sources of support to be from the hospital's own services and Macmillan (37%), with the next most common answer being that they didn't get any support from the listed sources (23%).

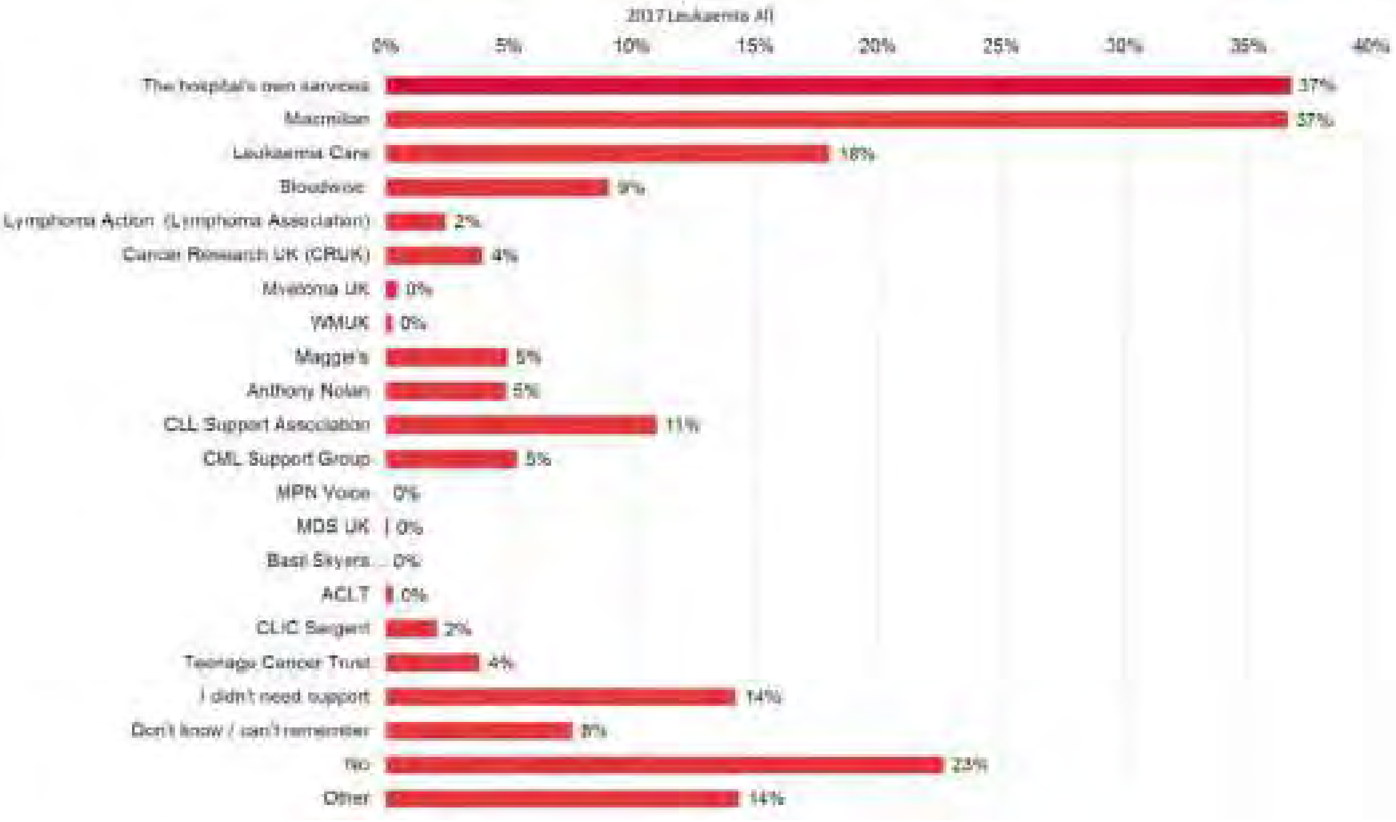

Figure 77: *Had support from the following organisations*

Patient cohort analysis

Looking at the difference between the three patient cohorts, the following can be observed:

- Respondents from Arms 2 and 3 were less likely to say they had received support from their hospital's own services
- All patient cohorts were as likely to contact Macmillan
- Respondents from Arms 2 and 3 were more likely to have received support from charities other than Macmillan
- Respondents from Arm 1 were more likely to say they didn't need support
- Respondents from Arm 1 were more likely to say they did not receive support from any of the listed sources

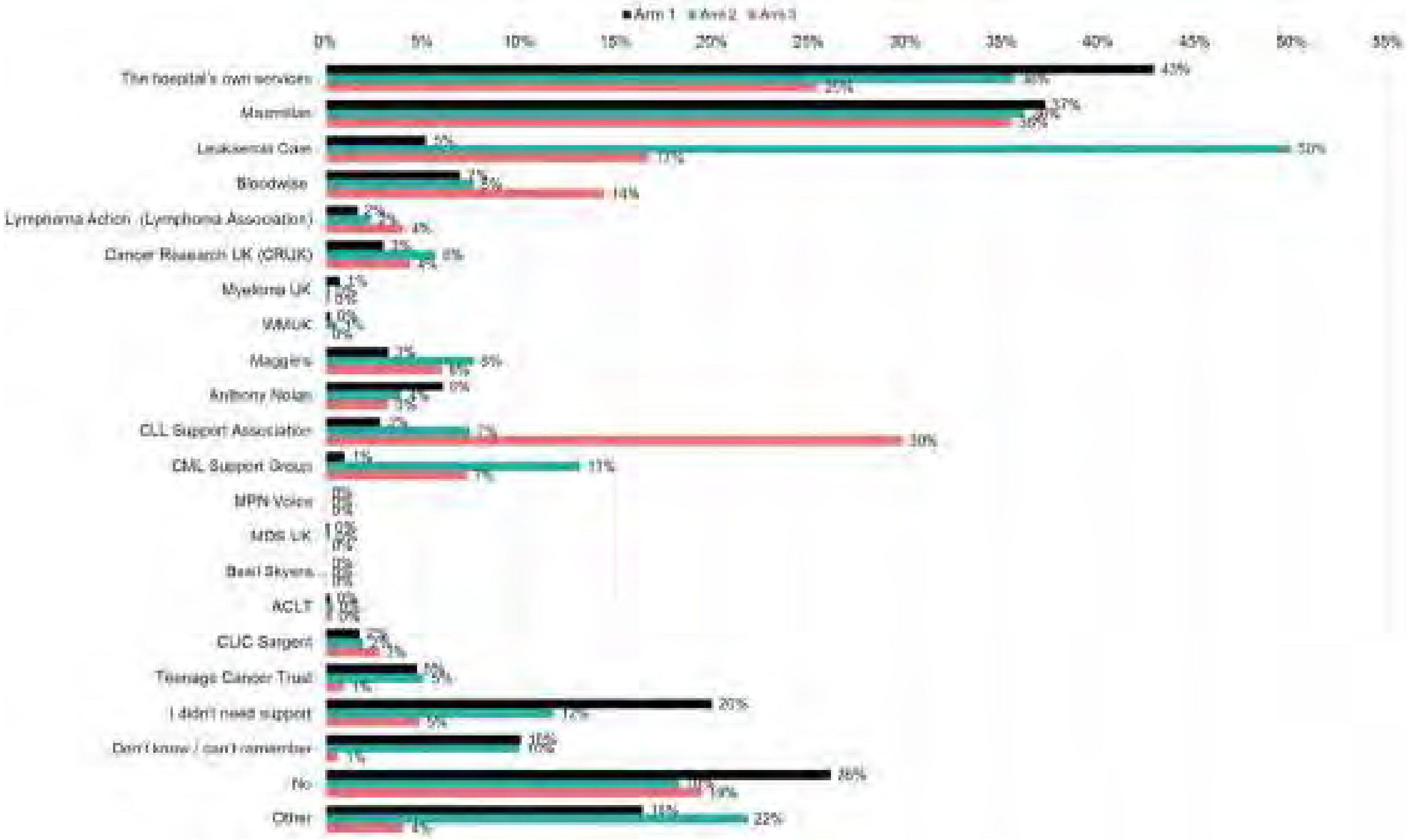

Figure 78: *Had support from the following organisations - by patient cohort*

4.6.6 Overall views of information given

Overall, 90% of respondents said the quality of the information they were given was either good, very good or excellent. The full breakdown can be seen below:

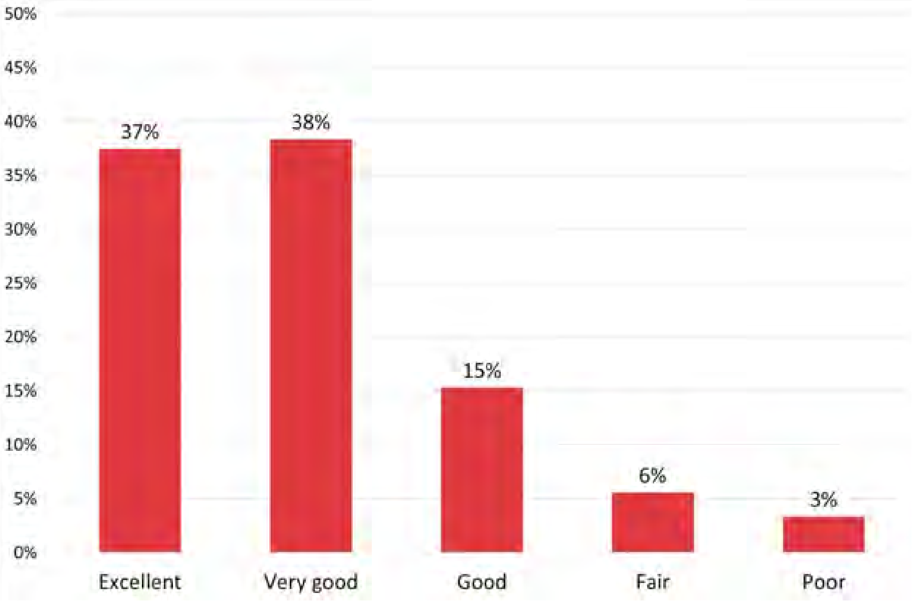

Figure 79: *Rating of quality of information given*

4.7 Care from GP after diagnosis

In 2017, we just wanted to look at two key questions in relation to care from General Practitioners (GP).

4.7.1 Were GPs given enough information from hospital

As in the 2016 survey, we asked whether respondents thought their GP was given enough information about their condition and treatment they had received at the hospital. Once again, most respondents (87%) said that their GP was given enough information (2016 score was 89%).

Respondents from Arms 2 and 3 were significantly less likely to think their GP was given enough information about their condition and hospital treatment (91% Arm1, 84% Arm 2 and 81% Arm3).

Once again, CML were least likely to report that this happened, 82% compared to the other types of leukaemia, which ranged between 83%-90%.

4.7.2 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. Just under two-thirds of respondents (66%) said that they regularly saw their GP and wanted this type of support; the majority of these (43%) said that they thought their GP practice definitely did all they could to support them. However, 11% felt more could have been done and almost one fifth (19%) said that their GP practice was of no help or support to them. These results are nearly identical to 2016.

Between leukaemia types, the response for those saying their general practice was of no help or support ranged from 14% (Other leukaemias) to 32% (ALL).

There are clear differences in experience between the three patient cohorts. As in the 2016 survey, the patient cohorts containing people who have reached out for support from Leukaemia Care and other charities/support groups, report poorer provision of support from their GP practice.

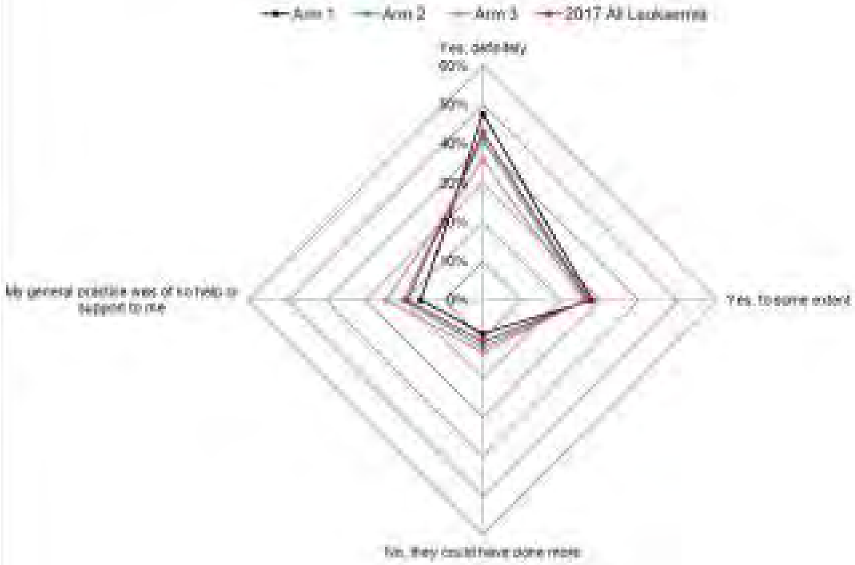

Figure 80: *Given enough support at general practice during cancer treatment - by patient cohort*

4.8 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.

4.8.1 Relapse

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

ALL – 14% had relapsed - 68% once, 5% 4 or more times
AML – 25% had relapsed - 86% once, 0% 4 or more times
CLL – 33% had relapsed – 52% once, 12% 4 or more times
CML – 19% had relapsed – 66% once, 4% 4 or more times
Other leukaemia - 29% had relapsed – 78% once, 4% 4 or more times

As in the 2016 survey, patients who report 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, as the chart below illustrates:

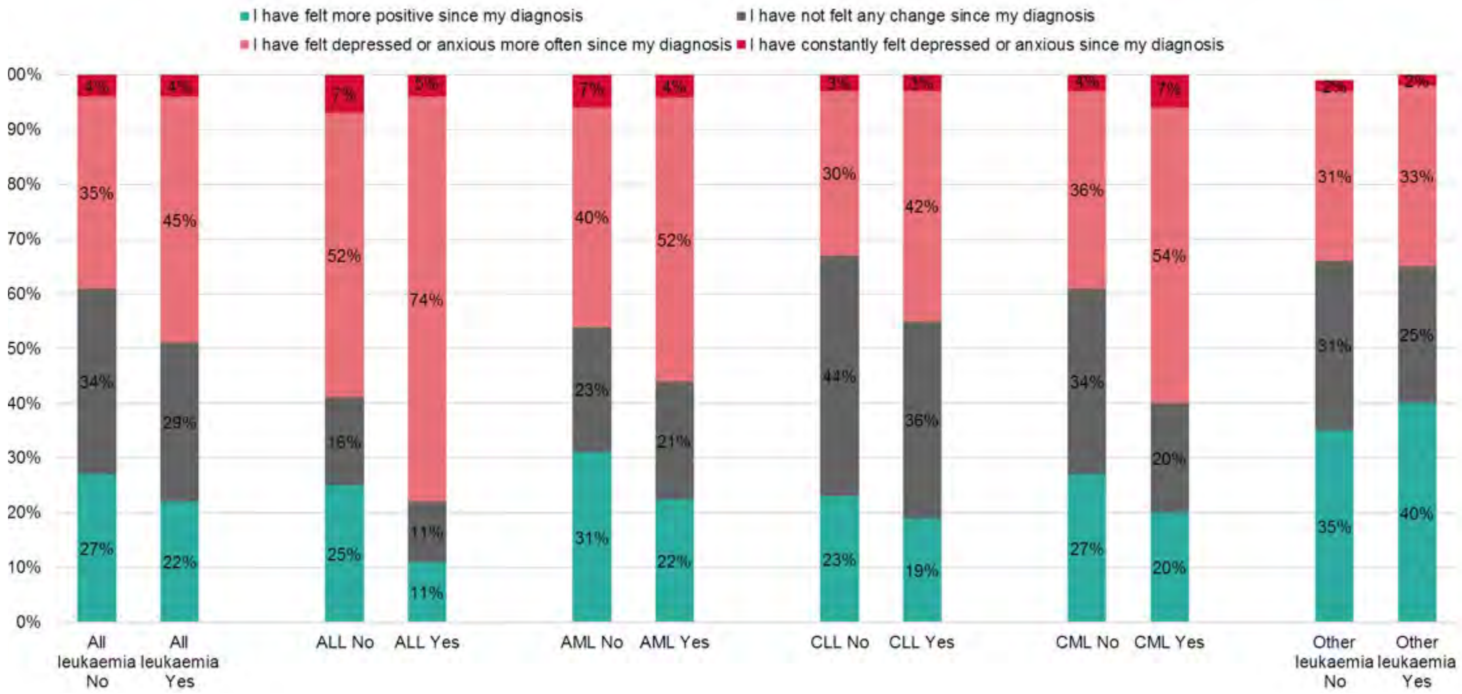

Figure 81: *Impact of leukaemia on emotional well-being - by leukaemia type and relapse status*

4.8.2 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 allogeneic 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.

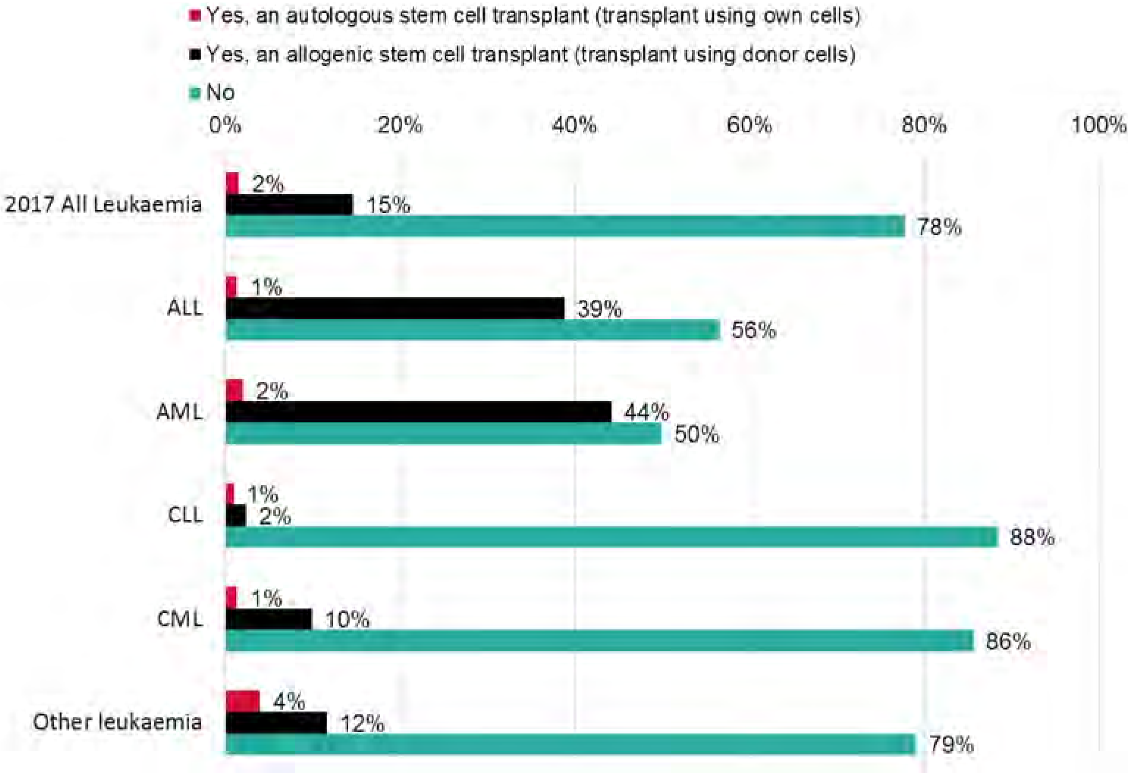

Figure 82: *Had a stem cell transplant - by leukaemia type*

4.9 Testing and monitoring

Leukaemia patients often undergo regular testing and/or monitoring to assess their response to treatment. For 2017, in this section of the questionnaire, we focussed mainly on respondents' experiences of bone marrow biopsies and aspirations.

4.9.1 Respondents undergoing bone marrow biopsy / aspiration

Overall, 81% of respondents had either a bone marrow biopsy or a bone marrow aspiration. In comparison to the other types of leukaemia, 33% of CLL respondents had not undergone either procedure.

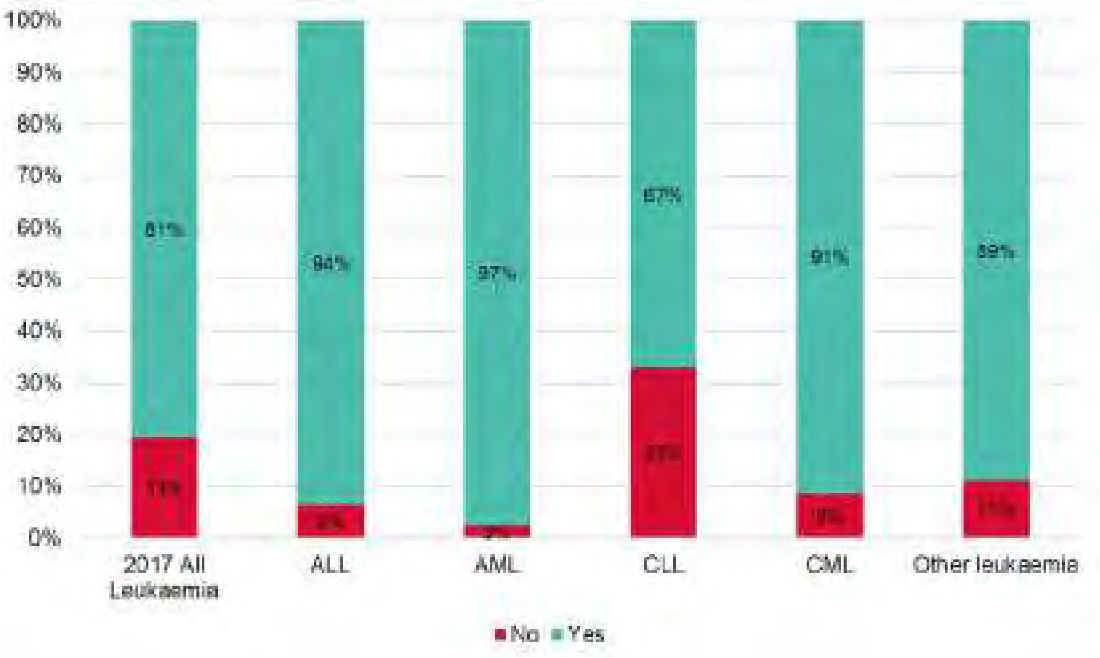

Figure 83: *Underwent bone marrow biopsy/aspiration - by leukaemia type*

Of those having one of the two procedures, 75% of respondents said they were offered pain relief and 25% said they were not offered any pain relief. CML respondents were less likely to report being offered pain relief compared to the other leukaemia types (69%).

Of those who were offered pain relief for their most recent procedure, 80% said they then went on to use it. From the respondents who weren't offered pain relief, just 13% said they went on to use it. Females were significantly more likely than males to say they used pain relief, despite there being little difference between the offer of pain relief between genders.

60% of respondents experienced moderate or severe pain during the procedure, and just 12% of people said that there was no pain.

4.9.2 Respondents undergoing tests for chromosome abnormalities

We asked respondents if they had undergone tests for chromosome abnormalities as part of their monitoring; 34% said "Yes" and 66% said "No". AML and CML respondents were more likely to say they had these tests.

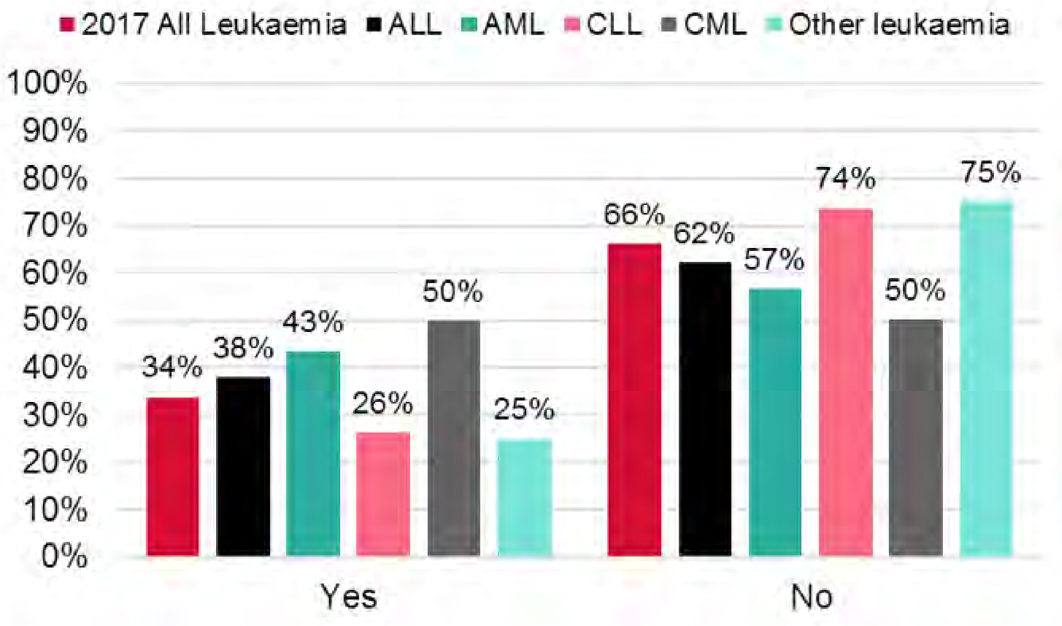

Figure 84: *Undergone tests for chromosome abnormalities - by leukaemia type*

4.10 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.

4.10.1 Treatment free periods

We asked respondents if they would consider it positive if a treatment plan contained a treatment-free period or included stopping treatment altogether. Except for CML, around half of respondents answered, 'Don't know' to this question.

Of those respondents who felt able to answer, 61% would consider it positive, and 39% would not. Respondents with a chronic leukaemia were more positive about this idea then acute respondents.

There are small increases in CLL and CML respondents saying yes since the 2016 survey:

- CLL - 2016 survey 59%, 2017 survey 64%
- CML – 2017 survey 68%, 2017 survey 72%

The full breakdown can be seen below:

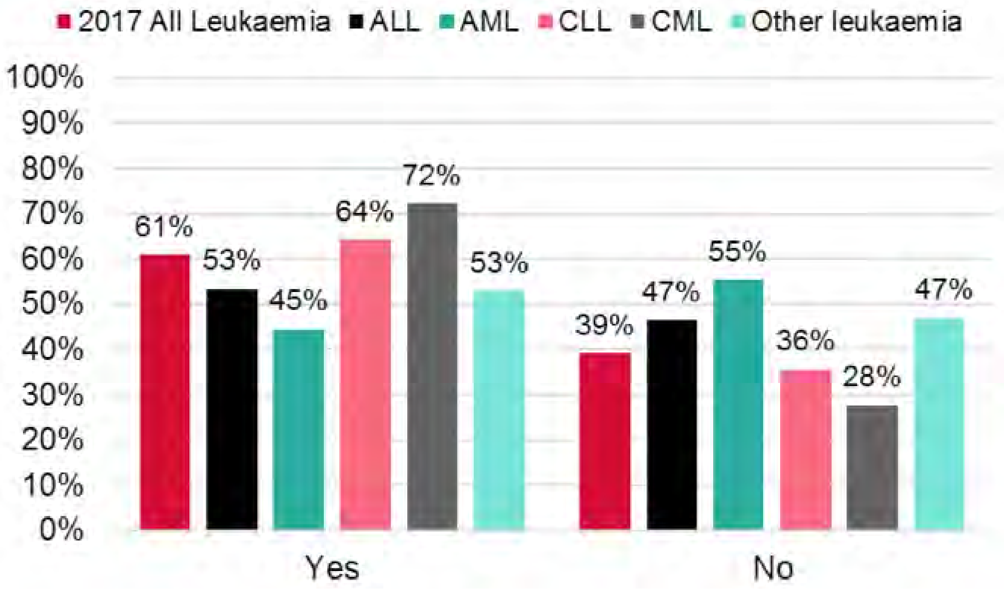

Figure 85: *Agreement that a treatment free period would be a positive - by leukaemia type*

4.10.2 Place of treatment

Overall, most respondents (61%) expressed that they would prefer to receive treatment as an outpatient. However, there were differences between the leukaemia types, as the chart below shows:

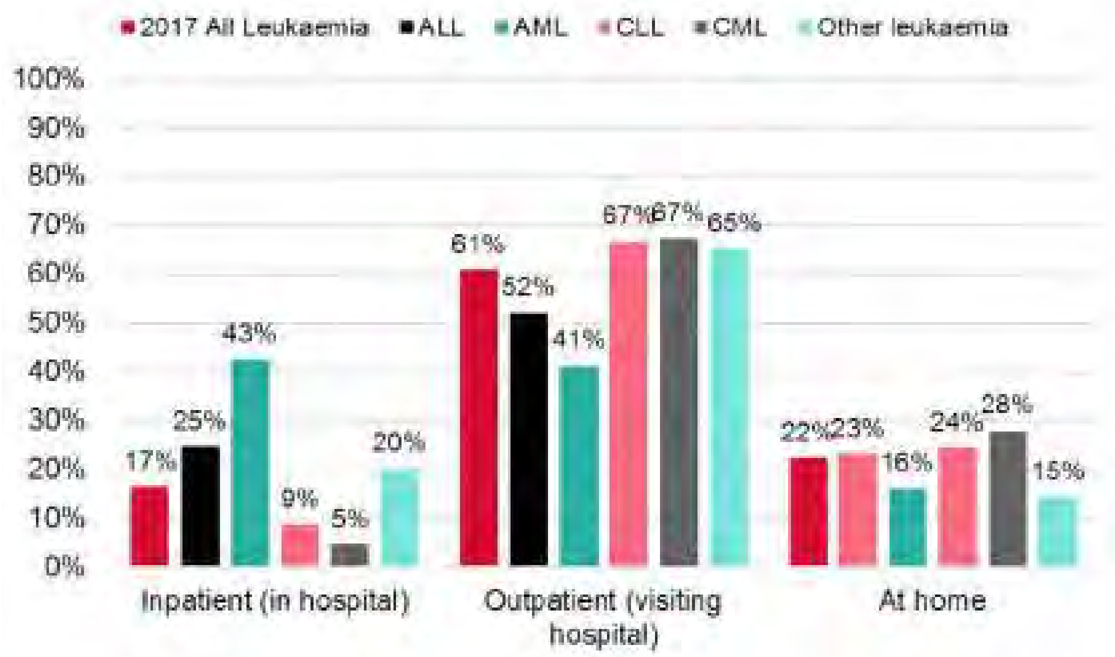

Figure 86: *Preference of where to receive treatment - by leukaemia type*

4.10.3 Treatment methods

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

Overall, over half (59%) of our respondents preferred an oral tablet and over a third (38%) said through an intravenous infusion.

We were interested to see if patients' current/most recent treatment method may influence what they put as their preferred, therefore we have compared the answers to this earlier question.

ALL patients' answers show a similar pattern to their current/most recent treatment method with an intravenous infusion or oral tablet being most popular. Injections were a less popular delivery method.

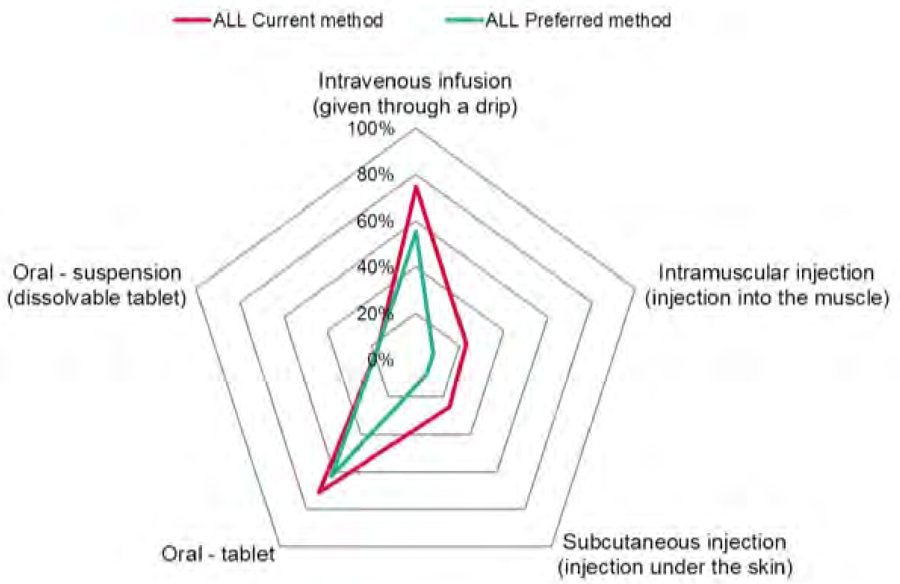

Figure 87: *Preferred treatment delivery method compared to current or previously used methods – by ALL*

AML preferred methods were also broadly in line with the current/most recent delivery method, although our results suggest that more patients would like the option of an oral suspension.

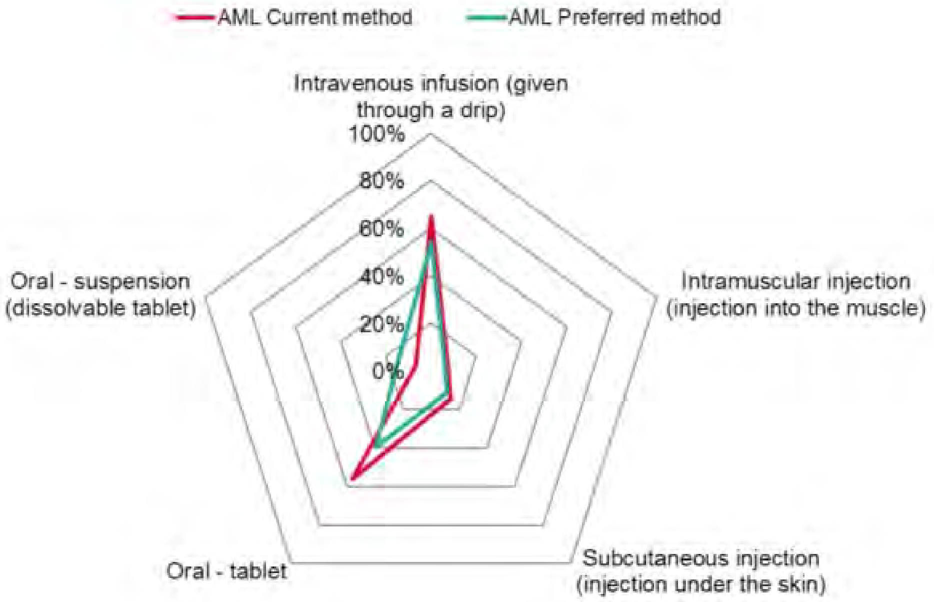

Figure 88: *Preferred treatment delivery method compared to current or previously used methods – by AML*

As with the acute leukaemias, intravenous infusion or oral tablet were the methods most CLL patients preferred. Compared to their current/most recent treatment, more would like the option of an oral suspension.

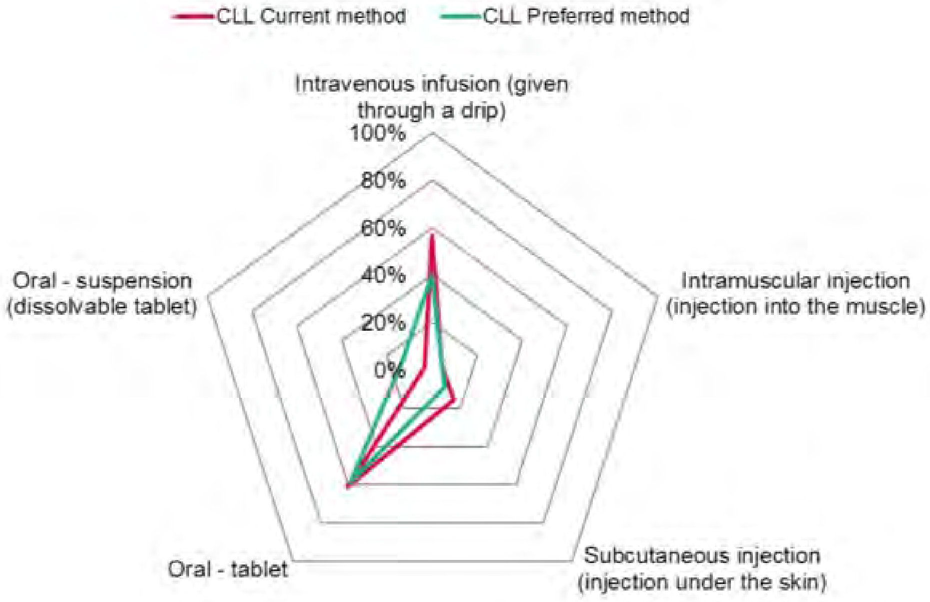

Figure 89: *Preferred treatment delivery method compared to current or previously used methods – by CLL*

The CML results show that, despite having used some other treatment delivery methods, most patients would prefer an oral tablet and are unlikely to consider the other options.

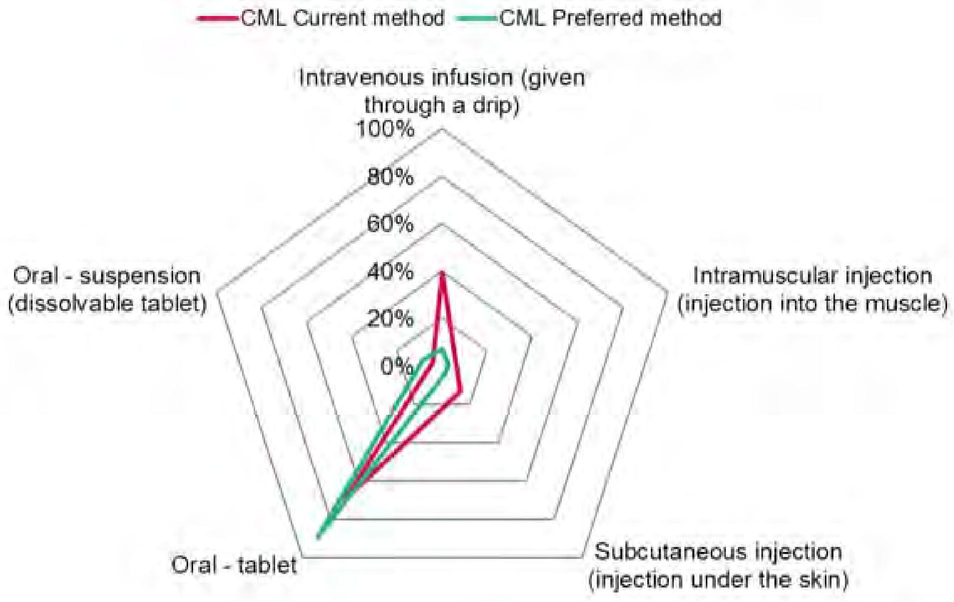

Figure 90: *Preferred treatment delivery method compared to current or previously used methods – by CML*

The ‘Other leukaemia’ also showed variation from reported current/most recent treatment method. Respondents indicate they would prefer a subcutaneous injection as much as an intravenous injection and also an oral suspension.

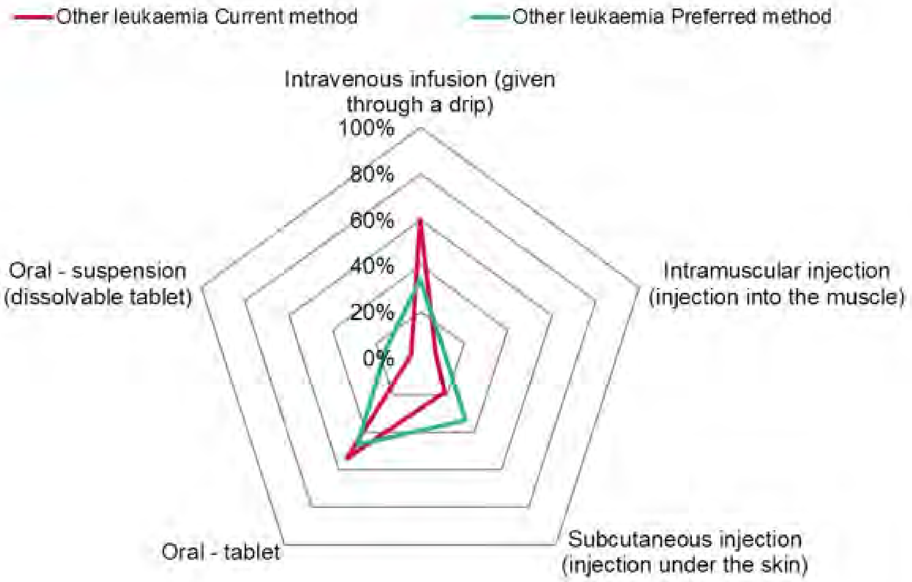

Figure 91: *Preferred treatment delivery method compared to current or previously used methods – by ‘Other leukaemia’*

4.10.4 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. As in 2016, there is not much difference between leukaemia types, except for CML respondents; in this group, only just under half (49%) 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.

4.10.5 Choice of different treatment options

Overall, 80% of respondents said they would like a choice of different treatment options. Once again CML had the lowest percentage of respondents; 68% wanted a choice compared to 77% ’Other leukaemia’, 79% ALL, 80% AML and 84% CLL.

4.10.6 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 (78%), followed by improved quality of life (69%). Just under a quarter (23%) of respondents selected a reduction of long term effects post treatment, but there is a significant difference in importance of this between acute and chronic patients – Acute 34% and Chronic 19%.

The full list can be seen below:

Improved/longer survival	78%
Improved quality of life	69%
Bring about a remission/response	57%
Tolerable side effects whilst on treatment	57%
Improved blood counts/test results	54%
Reduced impact on carer/family members	36%
Certainty of available treatment data/results	31%
Reduced long term effects post treatment	23%

In addition, the following differences were noted

- Acute patients were significantly more likely than chronic patients to select improved/longer survival
- Acute patients were significantly more likely than chronic patients to select reduced long-term effects post treatment

The tables below illustrate the importance of treatment features by age group and acute/chronic leukaemia.[4]

16-24 ACUTE	
Improved/longer survival	84%
Reduced long term effects post treatment	80%
Tolerable side effects whilst on treatment	76%
Bring about a remission/response	72%
Improved quality of life	68%
Improved blood counts/test results	48%
A reduced impact on carer/family members	40%
Certainty of available treatment data/results	40%

25-34 ACUTE	
Improved/longer survival	86%
Improved quality of life	81%
Improved blood counts/test results	75%
Tolerable side effects whilst on treatment	72%
Reduced long term effects post treatment	72%
Bring about a remission/response	69%
A reduced impact on carer/family members	56%
Certainty of available treatment data/results	47%

25-34 CHRONIC	
Improved quality of life	87%
Improved/longer survival	73%
Tolerable side effects whilst on treatment	73%
Improved blood counts/test results	60%
Bring about a remission/response	53%
Reduced long term effects post treatment	47%
A reduced impact on carer/family members	33%
Certainty of available treatment data/results	27%

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[4] The 85+ ACUTE and 16-24 CHRONIC results do not have enough replies to report on.

35-44 ACUTE	
Improved/longer survival	89%
Improved quality of life	82%
Bring about a remission/response	60%
Tolerable side effects whilst on treatment	60%
Reduced long term effects post treatment	60%
Improved blood counts/test results	58%
A reduced impact on carer/family members	56%
Certainty of available treatment data/results	31%

35-44 CHRONIC	
Improved/longer survival	84%
Improved quality of life	78%
Tolerable side effects whilst on treatment	76%
Bring about a remission/response	74%
Improved blood counts/test results	50%
A reduced impact on carer/family members	48%
Reduced long term effects post treatment	46%
Certainty of available treatment data/results	34%

45-54 ACUTE	
Improved/longer survival	95%
Improved quality of life	72%
Bring about a remission/response	70%
Tolerable side effects whilst on treatment	59%
Improved blood counts/test results	44%
A reduced impact on carer/family members	39%
Reduced long term effects post treatment	34%
Certainty of available treatment data/results	30%

45-54 CHRONIC	
Improved quality of life	86%
Improved/longer survival	84%
Tolerable side effects whilst on treatment	67%
Bring about a remission/response	67%
Improved blood counts/test results	47%
A reduced impact on carer/family members	42%
Certainty of available treatment data/results	37%
Reduced long term effects post treatment	29%

55-64 ACUTE	
Improved/longer survival	89%
Improved quality of life	76%
Bring about a remission/response	66%
Tolerable side effects whilst on treatment	62%
Improved blood counts/test results	50%
A reduced impact on carer/family members	44%
Certainty of available treatment data/results	34%
Reduced long term effects post treatment	31%

55-64 CHRONIC	
Improved/longer survival	84%
Improved quality of life	78%
Tolerable side effects whilst on treatment	64%
Bring about a remission/response	62%
Improved blood counts/test results	55%
A reduced impact on carer/family members	37%
Certainty of available treatment data/results	36%
Reduced long term effects post treatment	25%

65-74 ACUTE	
Improved/longer survival	78%
Improved quality of life	65%
Bring about a remission/response	59%
Improved blood counts/test results	53%
Tolerable side effects whilst on treatment	52%
A reduced impact on carer/family members	41%
Certainty of available treatment data/results	36%
Reduced long term effects post treatment	20%

65-74 CHRONIC	
Improved/longer survival	80%
Improved quality of life	68%
Tolerable side effects whilst on treatment	62%
Improved blood counts/test results	60%
Bring about a remission/response	60%
A reduced impact on carer/family members	34%
Certainty of available treatment data/results	34%
Reduced long term effects post treatment	16%

75-84 ACUTE	
Improved quality of life	70%
Improved/longer survival	65%
Improved blood counts/test results	54%
Bring about a remission/response	49%
Tolerable side effects whilst on treatment	30%
A reduced impact on carer/family members	19%
Certainty of available treatment data/results	8%
Reduced long term effects post treatment	8%

75-84 CHRONIC	
Improved/longer survival	65%
Improved quality of life	55%
Improved blood counts/test results	52%
Tolerable side effects whilst on treatment	43%
Bring about a remission/response	39%
A reduced impact on carer/family members	23%
Certainty of available treatment data/results	22%
Reduced long term effects post treatment	9%

85+ CHRONIC	
Improved blood counts/test results	76%
Improved quality of life	67%
Improved/longer survival	59%
Tolerable side effects whilst on treatment	47%
Bring about a remission/response	41%
A reduced impact on carer/family members	31%
Certainty of available treatment data/results	29%
Reduced long term effects post treatment	10%

Figure 92: *Important features of new treatments – by age group and acute/chronic leukaemia*

4.10.7 Treatment options available on the NHS

We asked respondents if they thought there are enough treatment options currently available on the NHS. Just over half felt able to give an opinion, and of these, 66% said yes there are and 34% said no.

There is a significant difference between the CPES cohort and the cohorts which have had contact with charities. 74% from Arm 1 thought there were enough treatment options available on the NHS compared to 62% from Arm 2, and 51% from Arm 3. As previously observed in the 2016 report, 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.

4.10.8 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. Most people, (82%) said that yes, they would consider it a positive. The exception is CML patients, where 65% felt this would be a positive aspect to a treatment.

5. Appendix 1 – Changes to the questionnaire

The original questionnaire was developed and designed over a number of months in 2016, following detailed discussion between Leukaemia Care and Quality Health. A number of changes were made for the 2017 survey, and these are detailed below:

21 questions removed[5]

Q8 When you were told your diagnosis, were you told about your particular type of blood cancer?
Q10 Had you heard of this overarching type of blood cancer e.g. leukaemia, before you were diagnosed?
Q12 What were you told about your prognosis or likely survival chances for your cancer?
Q18 Why did you eventually start treatment?
Q25 Were you hospitalised as a result of your side effects?
Q28 For what reason did you join the clinical trial?
Q29 For what reason did you not join the clinical trial?
Q32 How has your ability to move around been affected by your blood cancer diagnosis?
Q34 How has your diagnosis affected your ability to perform your daily routines (e.g. cooking, cleaning)?
Q35 How has your ability to self-care or your independence been affected by your diagnosis?
Q48 Did any of these organisations give particularly good or bad information?
Q51 If you think your treatment choices have been affected by the provision of information and support, why is this?
Q54 What was the nature of the support provided by your GPs and nurses at your general practice?
Q55 If you received no support from your GP and nurses at your general practice, please explain?
Q56 What has been the length of time in remission or response from your first/original treatment?
Q61 Are you currently undergoing regular testing or monitoring? E.g. blood counts, PCR or FISH testing
Q62 Approximately how often are you being tested or monitored?
Q63 Were the results of the test explained to you in a way you could understand?
Q64 Were you given a copy of your test results to take away with you?
Q68 As part of monitoring, have you had tests for chromosome abnormalities (mutation changes)?
Q69 What happened when you were given the results of these tests?

14 new questions[6]

Q10 At your first hospital appointment, were you told about your blood cancer subtype? E.g. CML, CLL, ALL, AML
Q14 What was your living situation at diagnosis?
Q20 How long were you on ‘watch and wait’?
Q21 How did you feel about having to start treatment?
Q25 Which treatment methods are you currently using or have previously received?
Q32 Were you in work or education before your diagnosis?

---

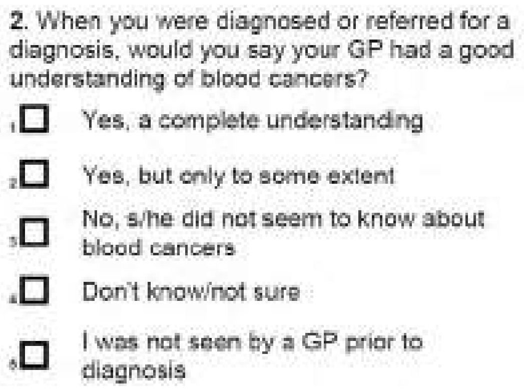
[5] The item numbers are from the 2016 questionnaire.
[6] The question numbers are from the new 2017 questionnaire.

Q34 What has been the long-term impact on your ability to work or complete education?
Q36 If your costs have increased, approx. by how much per month?

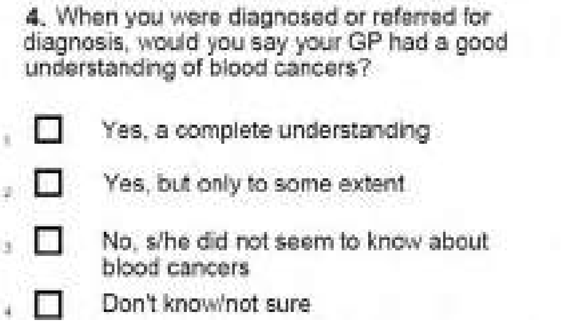
Q37 If your income has reduced, approx. by what percentage?
Q40 Please tick the statement that is most applicable to you:
Q42 What information were you given?
Q51 If you were given access to a Clinical Nurse Specialist, when was this?
Q62 Did you use pain relief for your most recent bone marrow biopsy/aspiration?
Q76 What is your highest level of qualification?

20 amendments[7]

Q1 Changed answer order
Q2 Moved to position **Q4** and changed:


2. When you were diagnosed or referred for a diagnosis, would you say your GP had a good understanding of blood cancers?

1 ☐ Yes, a complete understanding
2 ☐ Yes, but only to some extent
3 ☐ No, s/he did not seem to know about blood cancers
4 ☐ Don't know/not sure
6 ☐ I was not seen by a GP prior to diagnosis


4. When you were diagnosed or referred for diagnosis, would you say your GP had a good understanding of blood cancers?

1 ☐ Yes, a complete understanding
2 ☐ Yes, but only to some extent
3 ☐ No, s/he did not seem to know about blood cancers
4 ☐ Don't know/not sure

Q4 Moved[8] to position **Q2** in 2016 and changed from:


4. How long was it from the time you first started experiencing symptoms until you first saw a GP?

1 ☐ Less than a month
2 ☐ 1-3 months
3 ☐ 3–6 months
4 ☐ 7–12 months
5 ☐ 1-2 years
6 ☐ Over 2 years
7 ☐ I didn't think anything was wrong/I was asymptomatic
8 ☐ I didn't see my GP
9 ☐ Don't know/can't remember


2. How long was it from the time you first started experiencing symptoms until you first saw a healthcare professional?

1 ☐ Less than a month
2 ☐ 1-3 months
3 ☐ 3-6 months
4 ☐ 7-12 months
5 ☐ 1-2 years
6 ☐ Over 2 years
7 ☐ Don't know/can't remember

---

[7] The question numbers are the 2016 questionnaire.
[8] Due to questions being added and removed many questions have different question numbers. The ones noted here were deliberately repositioned within the survey.

Q5 changed:

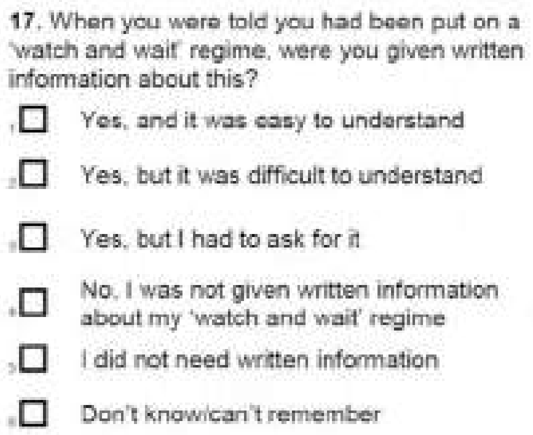
5. Before you were told you needed to go to hospital about cancer, how many times did you see your GP about the health problem caused by cancer?

- ☐ **None** – I went straight to hospital
- ☐ **None** – I went to hospital following a cancer screening appointment
- ☐ I saw my GP **once**
- ☐ I saw my GP **twice**
- ☐ I saw my GP **3 or 4** times
- ☐ I saw my GP **5 or more** times
- ☐ Don't know/can't remember

5. Before you were told you needed to go to hospital about cancer, how many times did you see your GP about the health problem caused by cancer?

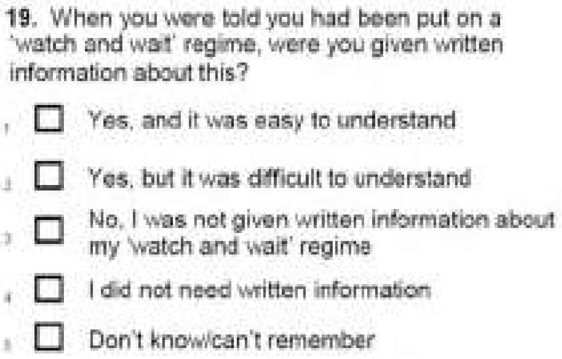
- ☐ **None** – I went straight to hospital
- ☐ **None** – I went to hospital following a cancer screening appointment
- ☐ I saw my GP **once**
- ☐ I saw my GP **twice**
- ☐ I saw my GP **3 or 4** times
- ☐ I saw my GP **5 or more** times
- ☐ Don't know/can't remember

Q17 moved to position **Q19** and changed from:



17. When you were told you had been put on a 'watch and wait' regime, were you given written information about this?

- ☐ Yes, and it was easy to understand
- ☐ Yes, but it was difficult to understand
- ☐ Yes, but I had to ask for it
- ☐ No, I was not given written information about my 'watch and wait' regime
- ☐ I did not need written information
- ☐ Don't know/can't remember

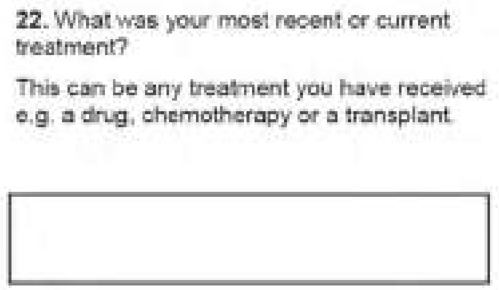


19. When you were told you had been put on a 'watch and wait' regime, were you given written information about this?

- ☐ Yes, and it was easy to understand
- ☐ Yes, but it was difficult to understand
- ☐ No, I was not given written information about my 'watch and wait' regime
- ☐ I did not need written information
- ☐ Don't know/can't remember

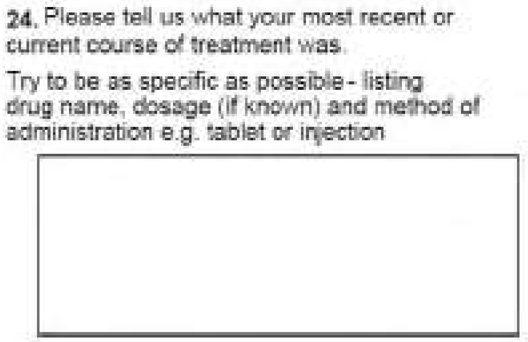
Q19 moved to position **Q15**

Q22 moved to position **Q24** and changed:



22. What was your most recent or current treatment?

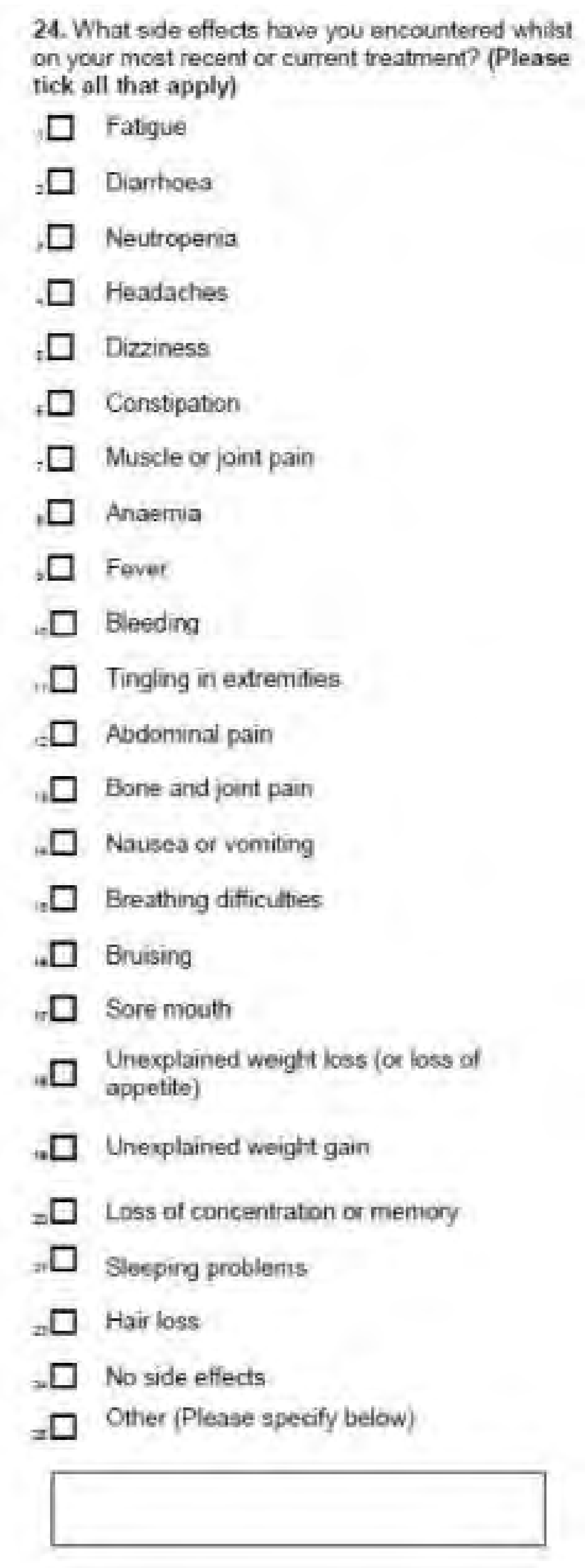
This can be any treatment you have received e.g. a drug, chemotherapy or a transplant



24. Please tell us what your most recent or current course of treatment was.

Try to be as specific as possible - listing drug name, dosage (if known) and method of administration e.g. tablet or injection

Q24 changed:



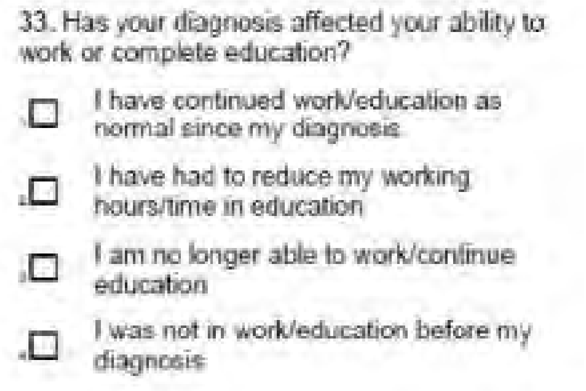
24. What side effects have you encountered whilst on your most recent or current treatment? **(Please tick all that apply)**

☐ Fatigue
☐ Diarrhoea
☐ Neutropenia
☐ Headaches
☐ Dizziness
☐ Constipation
☐ Muscle or joint pain
☐ Anaemia
☐ Fever
☐ Bleeding
☐ Tingling in extremities
☐ Abdominal pain
☐ Bone and joint pain
☐ Nausea or vomiting
☐ Breathing difficulties
☐ Bruising
☐ Sore mouth
☐ Unexplained weight loss (or loss of appetite)
☐ Unexplained weight gain
☐ Loss of concentration or memory
☐ Sleeping problems
☐ Hair loss
☐ No side effects
☐ Other (Please specify below)

27. What side effects have you encountered whilst on your most recent or current treatment? **(Please tick all that apply)**

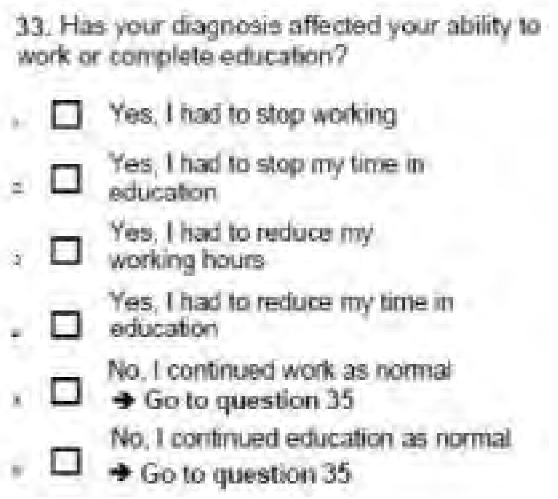
☐ Fatigue
☐ Neutropenia
☐ Headaches/dizziness
☐ Infections
☐ Constipation or diarrhoea
☐ Muscle, bone or joint pain
☐ Anaemia
☐ Fever
☐ Bleeding/Bruising
☐ Tingling in extremities
☐ Abdominal pain
☐ Nausea or vomiting
☐ Breathing difficulties
☐ Sore mouth
☐ Unexplained weight loss or gain
☐ Loss of concentration or memory
☐ Sleeping problems
☐ Hair loss
☐ Sepsis
☐ Itchy skin/rashes
☐ Depression/anxiety
☐ No side effects
☐ Other (Please specify below)

Q30 changed answer order
Q33 changed:



33. Has your diagnosis affected your ability to work or complete education?

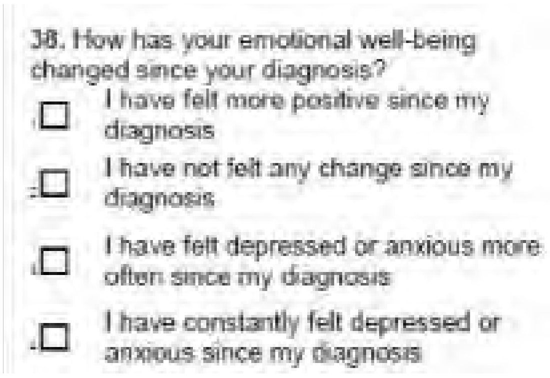
☐ I have continued work/education as normal since my diagnosis
☐ I have had to reduce my working hours/time in education
☐ I am no longer able to work/continue education
☐ I was not in work/education before my diagnosis



33. Has your diagnosis affected your ability to work or complete education?

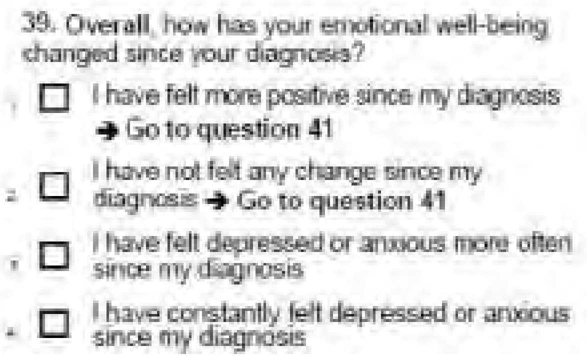
☐ Yes, I had to stop working
☐ Yes, I had to stop my time in education
☐ Yes, I had to reduce my working hours
☐ Yes, I had to reduce my time in education
☐ No, I continued work as normal ➔ Go to question 35
☐ No, I continued education as normal ➔ Go to question 35

Q38 changed:



38. How has your emotional well-being changed since your diagnosis?

☐ I have felt more positive since my diagnosis
☐ I have not felt any change since my diagnosis
☐ I have felt depressed or anxious more often since my diagnosis
☐ I have constantly felt depressed or anxious since my diagnosis



39. Overall, how has your emotional well-being changed since your diagnosis?

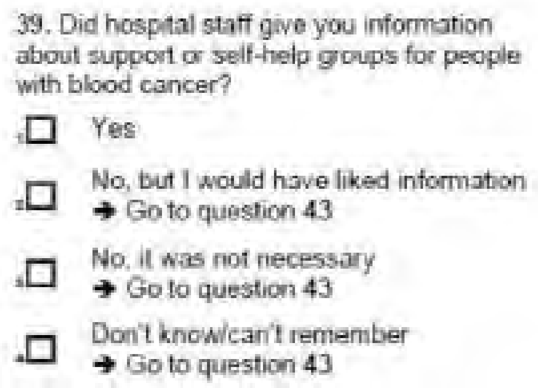
☐ I have felt more positive since my diagnosis ➔ Go to question 41
☐ I have not felt any change since my diagnosis ➔ Go to question 41
☐ I have felt depressed or anxious more often since my diagnosis
☐ I have constantly felt depressed or anxious since my diagnosis

The section of the survey **'Support for People with Blood Cancer'** included a new introduction:

"This section asks about information you may have been given when your treatment for blood cancer first started; please include any information provided. This could be information on emotional support, practical information or information about your cancer etc.

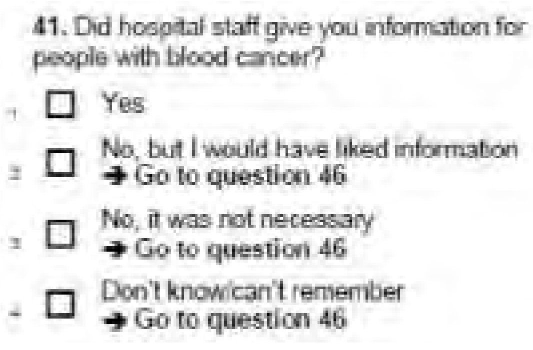
Thinking about when your treatment for blood cancer first started..."

Q39 changed:



39. Did hospital staff give you information about support or self-help groups for people with blood cancer?

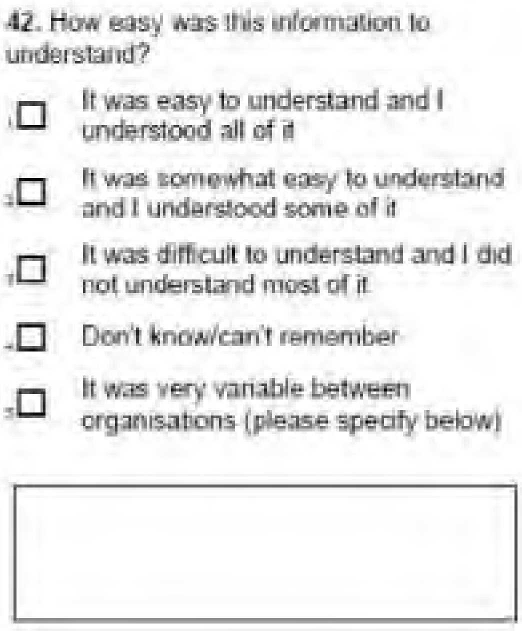
☐ Yes
☐ No, but I would have liked information ➔ Go to question 43
☐ No, it was not necessary ➔ Go to question 43
☐ Don't know/can't remember ➔ Go to question 43



41. Did hospital staff give you information for people with blood cancer?

☐ Yes
☐ No, but I would have liked information ➔ Go to question 46
☐ No, it was not necessary ➔ Go to question 46
☐ Don't know/can't remember ➔ Go to question 46

Q42 changed:



42. How easy was this information to understand?

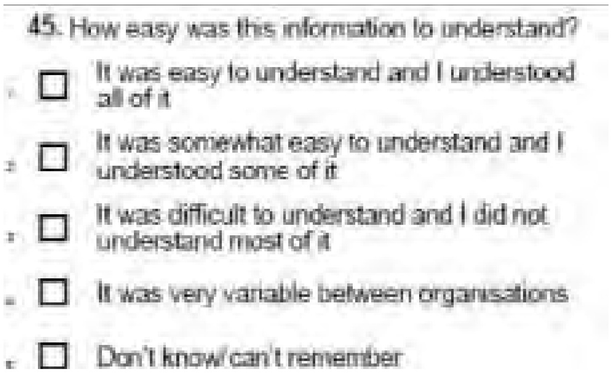
☐ It was easy to understand and I understood all of it

☐ It was somewhat easy to understand and I understood some of it

☐ It was difficult to understand and I did not understand most of it

☐ Don't know/can't remember

☐ It was very variable between organisations (please specify below)



45. How easy was this information to understand?

☐ It was easy to understand and I understood all of it

☐ It was somewhat easy to understand and I understood some of it

☐ It was difficult to understand and I did not understand most of it

☐ It was very variable between organisations

☐ Don't know/ can't remember

Q46 moved to position **Q52** and changed:

46. Did you get support from any of the followir organisations? (Please tick all that apply)

☐ The hospital's own services

☐ Macmillan

☐ Leukaemia CARE

☐ Bloodwise (previously known as Leukaemia and Lymphoma Research)

☐ Lymphoma Association

☐ Cancer Research UK (CRUK)

☐ Myeloma UK

☐ WMUK

☐ Maggie's

☐ Anthony Nolan

☐ CLL Support Association

☐ CML Support Group

☐ MPN Voice

☐ MDS UK

☐ Basil Skyers Myeloma Foundation

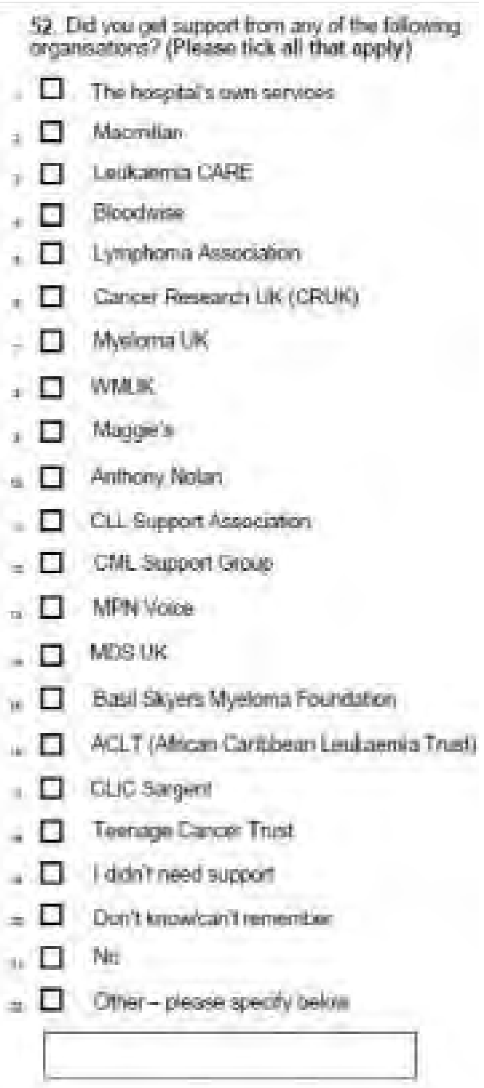
☐ ACLT (African Caribbean Leukaemia Trust)

☐ I didn't need support

☐ Don't know/can't remember

☐ No

☐ Other – please specify below



52. Did you get support from any of the following organisations? (Please tick all that apply)

☐ The hospital's own services

☐ Macmillan

☐ Leukaemia CARE

☐ Bloodwise

☐ Lymphoma Association

☐ Cancer Research UK (CRUK)

☐ Myeloma UK

☐ WMUK

☐ Maggie's

☐ Anthony Nolan

☐ CLL Support Association

☐ CML Support Group

☐ MPN Voice

☐ MDS UK

☐ Basil Skyers Myeloma Foundation

☐ ACLT (African Caribbean Leukaemia Trust)

☐ CLIC Sargent

☐ Teenage Cancer Trust

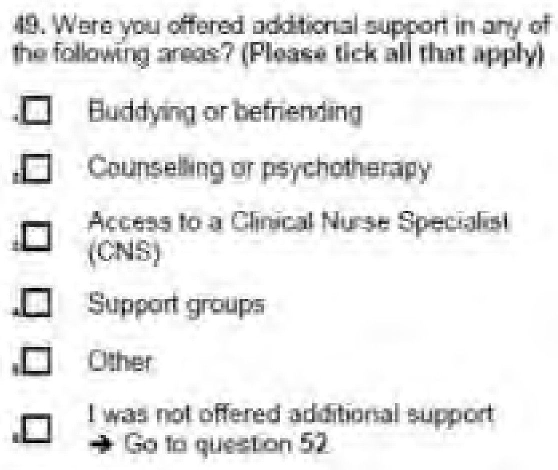
☐ I didn't need support

☐ Don't know/can't remember

☐ No

☐ Other – please specify below

Q49 changed:



49. Were you offered additional support in any of the following areas? **(Please tick all that apply)**

☐ Buddying or befriending

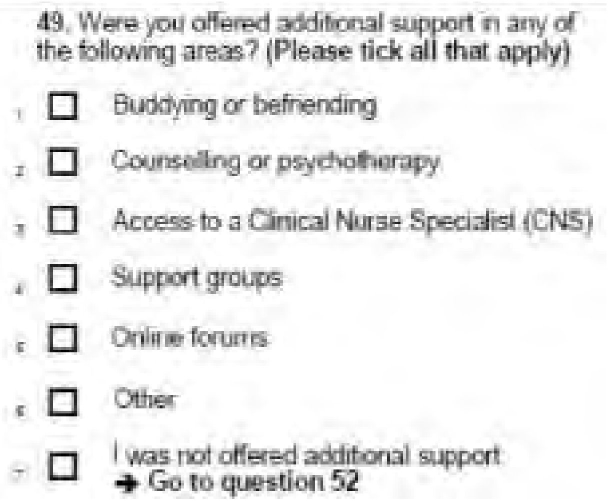
☐ Counselling or psychotherapy

☐ Access to a Clinical Nurse Specialist (CNS)

☐ Support groups

☐ Other

☐ I was not offered additional support ➔ Go to question 52



49. Were you offered additional support in any of the following areas? **(Please tick all that apply)**

☐ Buddying or befriending

☐ Counselling or psychotherapy

☐ Access to a Clinical Nurse Specialist (CNS)

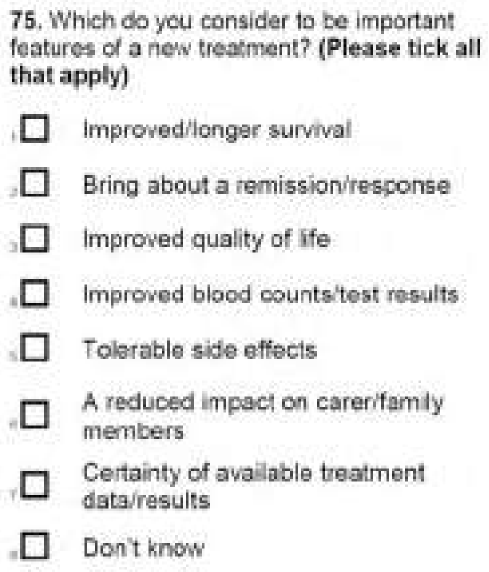
☐ Support groups

☐ Online forums

☐ Other

☐ I was not offered additional support ➔ **Go to question 52**

Q60 moved to **Q56**
Q75 changed:



75. Which do you consider to be important features of a new treatment? **(Please tick all that apply)**

☐ Improved/longer survival

☐ Bring about a remission/response

☐ Improved quality of life

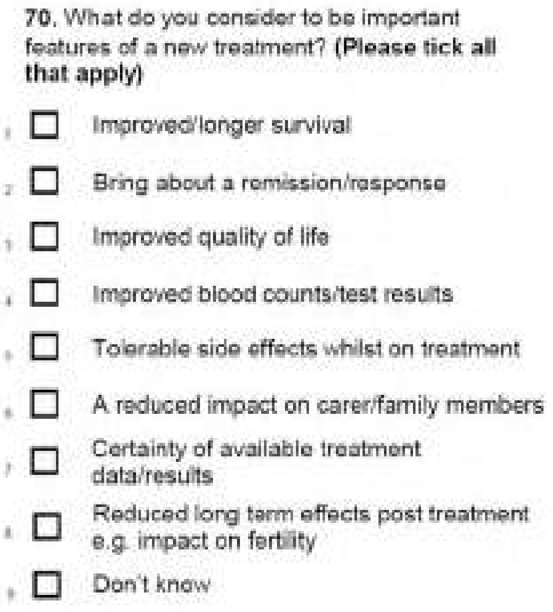
☐ Improved blood counts/test results

☐ Tolerable side effects

☐ A reduced impact on carer/family members

☐ Certainty of available treatment data/results

☐ Don't know



70. What do you consider to be important features of a new treatment? **(Please tick all that apply)**

☐ Improved/longer survival

☐ Bring about a remission/response

☐ Improved quality of life

☐ Improved blood counts/test results

☐ Tolerable side effects whilst on treatment

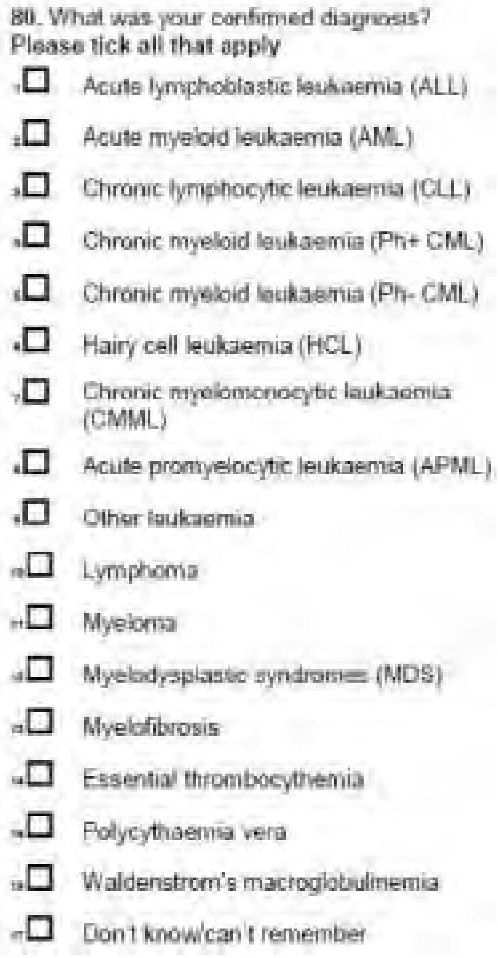
☐ A reduced impact on carer/family members

☐ Certainty of available treatment data/results

☐ Reduced long term effects post treatment e.g. impact on fertility

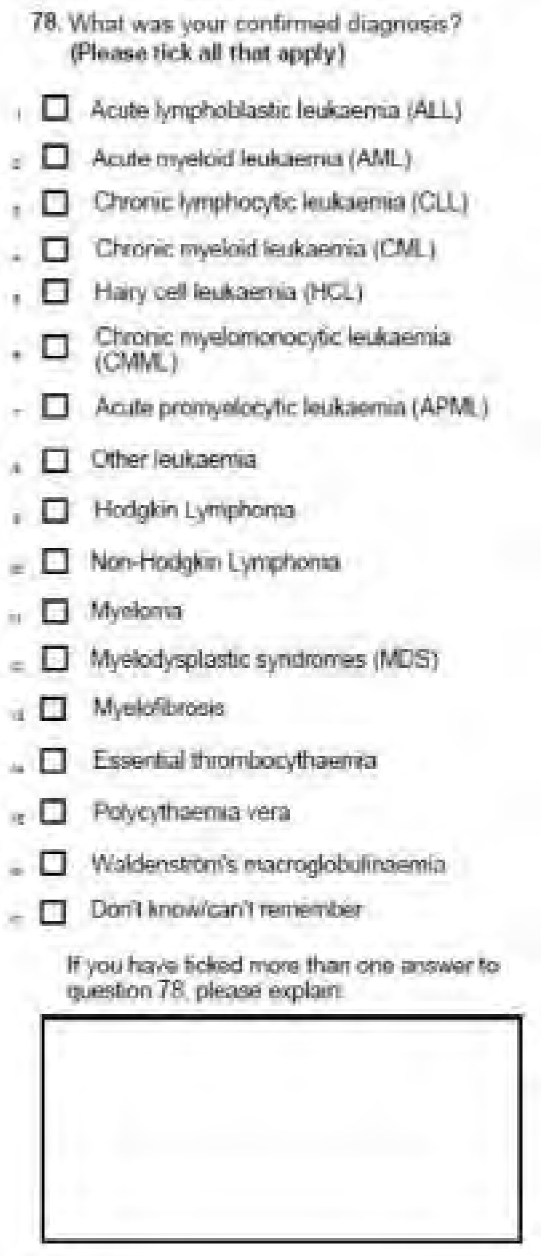
☐ Don't know

Q80 changed:



80. What was your confirmed diagnosis?
Please tick all that apply

- ☐ Acute lymphoblastic leukaemia (ALL)
- ☐ Acute myeloid leukaemia (AML)
- ☐ Chronic lymphocytic leukaemia (CLL)
- ☐ Chronic myeloid leukaemia (Ph+ CML)
- ☐ Chronic myeloid leukaemia (Ph- CML)
- ☐ Hairy cell leukaemia (HCL)
- ☐ Chronic myelomonocytic leukaemia (CMML)
- ☐ Acute promyelocytic leukaemia (APML)
- ☐ Other leukaemia
- ☐ Lymphoma
- ☐ Myeloma
- ☐ Myelodysplastic syndromes (MDS)
- ☐ Myelofibrosis
- ☐ Essential thrombocythemia
- ☐ Polycythaemia vera
- ☐ Waldenstrom's macroglobulinemia
- ☐ Don't know/can't remember



78. What was your confirmed diagnosis?
(Please tick all that apply)

- ☐ Acute lymphoblastic leukaemia (ALL)
- ☐ Acute myeloid leukaemia (AML)
- ☐ Chronic lymphocytic leukaemia (CLL)
- ☐ Chronic myeloid leukaemia (CML)
- ☐ Hairy cell leukaemia (HCL)
- ☐ Chronic myelomonocytic leukaemia (CMML)
- ☐ Acute promyelocytic leukaemia (APML)
- ☐ Other leukaemia
- ☐ Hodgkin Lymphoma
- ☐ Non-Hodgkin Lymphoma
- ☐ Myeloma
- ☐ Myelodysplastic syndromes (MDS)
- ☐ Myelofibrosis
- ☐ Essential thrombocythaemia
- ☐ Polycythaemia vera
- ☐ Waldenstrom's macroglobulinaemia
- ☐ Don't know/can't remember

If you have ticked more than one answer to question 78, please explain

Q81 changed:

81. To which of these ethnic groups would you say you belong? (Tick ONE only)

a. WHITE

- ☐ English/Welsh/Scottish/Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish traveller
- ☐ Any other White background (Please specify below)

b. MIXED

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/multiple ethnic background (Please specify below)

c. ASIAN OR ASIAN BRITISH

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background (Please specify below)

d. BLACK OR BLACK BRITISH

- ☐ Caribbean
- ☐ African
- ☐ Any other Black/African/Caribbean background (Please specify below)

e. OTHER ETHNIC GROUP

- ☐ Arab
- ☐ Any other ethnic group (Please specify below)

75. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

1 ☐ White
2 ☐ Mixed
3 ☐ Asian/Asian British
4 ☐ Black/Black British
5 ☐ Other ethnic group

6. Appendix 2 – Additional breakdown data

Charity data responses compared to CPES data responses

This section summarises the main significant differences between the combined 'charity' arms (Arms 2 and 3) compared to Arm 1.

It should be noted that Arms 2 and 3 contained a smaller percentage of AML patients, (14%, compared to 24% Arm 1) and a much larger percentage of CML patients, (24%, compared to 9% in Arm 1). This may be a contributing factor to some of the differences in the results.

In more detail, those responding to the survey from the 'charity' arms are:

More likely to experience the following symptoms (question 1):

- **Fatigue** 58%, compared to 53% Arm 1
- **Frequent and repeated infections** 23%, compared to 17% Arm 1
- **Sleeping problems** 19%, compared to 16% Arm 1
- **Headaches** 11%, compared to 8% Arm 1
- **Pain in bones/joints** 23%, compared to 18% Arm 1
- **Swollen stomach or abdominal discomfort** 14%, compared to 9% Arm 1
- **Palpitations/heart irregularities** 7%, compared to 5% Arm 1

Less likely to experience the following symptoms (question 1):

- **Swollen lymph nodes** 17%, compared to 20% Arm 1
- **Another symptom not listed** 12%, compared to 15% Arm 1

Less likely to wait **less than a month** from experiencing symptoms until seeing a health professional (question 2), (32%, compared to 40% Arm 1); and more likely to wait between **7-12 months** (9%, compared to 5% Arm 1); and 1-2 years (7%, compared to 5% Arm 1)

Less likely to say their route to diagnosis (question 3) was being seen as an **Emergency/A&E patient** (8%, compared to 12% Arm 1); and more likely for their **GP to start treating them for another condition** (22%, compared to 16% Arm 1)

Less likely to say that their GP had a **complete understanding** of blood cancers (question 4), (37%, compared to 60% Arm 1); more likely to say their **GP only knew about them to some extent** (45%, compared to 30% Arm 1); or **did not seem to know about blood cancers** (17%, compared to 11% Arm 1)

More likely to see their GP **five or more times** before being told they needed to go to hospital (question 5), (12%, compared to 8% Arm 1)

Less likely to wait **1-3 months** from seeing a GP to being diagnosed (question 6), (17%, compared to 21%); and more likely to wait **1-2 years** (3%, compared to 1%)

Less likely to say that they **completely understood** the explanation of what was wrong with them (question 11), (36%, compared to 50% Arm 1); and more likely to say they **only partially** understood the explanation (53%, compared to 45% Arm 1); or **did not understand** the explanation (11%, compared to 5% Arm 1)

More likely to say that they were told their diagnosis **by phone by their GP** (question 12), (8%, compared to 5% Arm 1); and less likely to say they were told in **person at the hospital** (77%, compared to 82% Arm 1)

Less likely to have a **son or daughter** with them at diagnosis, (question 13), (4%, compared to 7% Arm 1)

Less likely to say that they were **definitely** involved as much as they wanted to be in decisions about their treatment and care (question 15), (68%, compared to 83% Arm 1); and more likely to say they were only involved **to some extent** (25%, compared to 15% Arm 1); or **not involved as much as they wanted** (8%, compared to 2% Arm 1)

Less likely to say that they f**ully understood** the reasons for being placed on 'watch and wait' (question 17), (52%, compared to 68% Arm 1); and more likely to say they **mostly understood** the reasons (38%, compared to 28% Arm 1); or they **did not understand** the reasons (10%, compared to 3% Arm 1)

More likely to say that they were v**ery concerned/worried** about being placed on 'watch and wait' (question 18), (16%, compared to 5% Arm 1) or they had **some concerns and worries** (48%, compared to 38% Arm 1) and less likely to say they **did not have any concerns or worries** (36%, compared to 57% Arm 1)

Less likely to say that they were **given understandable written information** about 'watch and wait' (question 19), (47%, compared to 64% Arm 1) and more likely to say they were **not given written information** (41%, compared to 28% Arm 1)

More likely to say that **treatment hasn't started yet as 'watch and wait' continues**, (question 20), (49%, compared to 5% Arm 1)

Less likely to say that they felt **positive about starting treatment** (question 21), (29%, compared to 41% Arm 1) and more likely to say they felt **mixed emotions** (48%, compared to 40% Arm 1)

Less likely to be offered a **choice of treatment options** (question 23), (29%, compared to 35% Arm 1)

More likely to say they have used an **oral tablet** treatment method (question 25), (66%, compared to 58% Arm1)

More likely to experience the following side effects (question 27):

- **Fatigue** 68%, compared to 60% Arm 1
- **Neutropenia** 32%, compared to 25% Arm 1
- **Headaches/dizziness** 25%, compared to 18% Arm 1
- **Infections** 35%, compared to 30% Arm 1
- **Muscle, bone or joint pains** 39%, compared to 30% Arm 1
- **Abdominal pain** 13%, compared to 10% Arm 1
- **Nausea or vomiting** 34%, compared to 27% Arm 1
- **Loss of concentration or memory** 28%, compared to 22% Arm 1
- **Depression/anxiety** 24%, compared to 19% Arm 1

Less likely to experience the following side effects (question 27):

- **Another side effect not listed** 9%, compared to 14% Arm 1

More likely to say the side effects of their most recent or current treatment had a **large impact** (question 28), (38%, compared to 32% Arm 1)

More likely **to not be offered the option to participate in a clinical trial** (question 29), (57%, compared to 52% Arm 1)

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

- **Fatigue** 69%, compared to 64% Arm 1
- **Frequent and repeated infections** 29%, compared to 25% Arm 1
- **Sleeping problems** 37%, compared to 30% Arm 1
- **Fever/night sweats** 31%, compared to 28% Arm 1
- **Pain in bones/joints** 38%, compared to 29% Arm 1
- **Swollen stomach or abdominal discomfort** 18%, compared to 15% Arm 1
- **Memory/loss of concentration** 29%, compared to 21% Arm 1
- **Palpitations/heart irregularities** 14%, compared to 11% Arm 1
- **Muscle pain** 26%, compared to 20% Arm 1
- **Back/lower back pain** 26%, compared to 22% Arm 1

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

- **No symptoms** 11%, compared to 17% Arm 1
- **Another symptom not listed** 13%, compared to 17% Arm 1

More likely to experience **regular pain** as a direct result of their condition (question 31), (19%, compared to 13% Arm 1) or **constant** pain (6%, compared to 4% Arm 1) and less likely to experience **no pain** (45%, compared to 57% Arm 1)

Less likely to have had to **stop working** as a result of their diagnosis (question 32), (38%, compared to 53% Arm 1) or **reduce their working hours** (21%, compared to 15% Arm 1), and more likely to continue work as normal (36%, compared to 28%)

More likely to experience a **positive financial impact** as a result of their cancer (question 35), (6%, compared to 4% Arm 1) and less likely to experience **no impact on spending/income** (50%, compared to 54% Arm 1)

Less likely to report the **lowest costs increase** - £1- £250 (question 36), (60%, compared to 69% Arm 1)

Less likely to choose **not to travel** since diagnosis (question 38), (14%, compared to 18%)

More likely to have felt depressed or anxious **constantly** since their diagnosis (question 39), (6%, compared to 3% Arm 1); or **more often** (47%, compared to 34% Arm 1), and less likely to experience **no change** in their emotional well-being (28%, compared to 36% Arm 1), or felt **more positive** (20%, compared to 26%)

Less likely to say that they were **given information** for people with blood cancer about support or self-help groups (question 41), (87%, compared to 96% Arm 1) and more likely to say they were **not given information but would have liked it** (13%, compared to 4% Arm 1)

Less likely to be given the following information (question 42):

- **Information on emotional support** 42%, compared to 49% Arm 1

- **Practical information** 56%, compared to 64% Arm 1

More likely to be given the following information (question 42):
- **Information about their blood cancer** 91%, compared to 87% Arm 1

More likely to say that they were given just **written information** (question 43), (26%, compared to 20% Arm 1)

More likely to be given information at **diagnosis** (question 44), (58%, compared to 49% Arm 1) and less likely **before starting treatment** (35%, compared to 53% Arm 1); **during treatment** (31%, compared to 39% Arm 1); **after treatment** (10%, compared to 16% Arm 1) or at **all time points** (22%, compared to 28% Arm 1)

Less likely to say they **understood all** information they were given (question 45), (49%, compared to 61% Arm 1) and more likely just to **understand some** of it (43%, compared to 34% Arm 1)

Less likely to be told by their diagnosing health professional to find further information by **coming back to the hospital** (question 46), (22%, compared to 33% Arm 1) and more likely to have been recommended Leukaemia Care (18%, compared to 11% Arm 1) or **not to have been recommended anything** (34%, compared to 23% Arm 1)

More likely to have been told by their diagnosing health professional to **look on Internet but only at trusted websites** (25%, compared to 15% Arm 1) and less likely **not to have anything said to them about the Internet (64%, compared to 73% Arm 1)**

More likely to have **used the Internet** and found further, **useful information** (question 48), (62%, compared to 42% Arm 1) but also to have found the **information inaccurate or not up-to-date** (6%, compared to 3%). They were less likely to **not have used the Internet** to find further information (27%, compared to 50% Arm 1)

More likely to be offered additional support in the following areas (question 49):
- **Support groups** 22%, compared to 19% Arm 1
- **Online forums** 6%, compared to 3% Arm 1

More likely to **not be offered additional support** (question 49), (36% compared to 26% Arm 1)

Less likely **to be offered access to a Clinical Nurse Specialist** (question 49), (54% compared to 69% Arm 1)

More likely to have accessed additional support but **not felt better/more positive** as a result (question 50), (16%, compared to 8% Arm 1) and less likely to say they **did not access the support** (36%, compared to 26% Arm 1)

Less likely to be given access to a CNS **before starting treatment** (question 51), (31%, compared to 44% Arm 1); **after treatment** (9%, compared to 15% Arm 1) or **at all time points** (23%, compared to 32% Arm 1)

More likely to have said they got support from (question 52):
- **Leukaemia Care** 32%, compared to 5% Arm 1
- **Bloodwise** 11%, compared to 7% Arm 1

- **Cancer Research UK (CRUK)** 5%, compared to 3% Arm 1
- **Maggie's** 7%, compared to 3% Arm 1
- **CLL Support Association** 20%, compared to 3% Arm 1
- **CML Support Group** 10%, compared to 1% Arm 1

Less likely to have said they got support from (question 52):

- **Anthony Nolan** 4%, compared to 6% Arm 1
- **Teenage Cancer Trust** 3%, compared to 5% Arm 1
- **Another charity not listed** 12%, compared to 16% Arm 1

Less likely to have said they **didn't need support** (question 52), (8%, compared to 20%)

Less likely to have said they **didn't get support** (question 52), (12%, compared to 16%)

Less likely to say the information they were given was **excellent** (question 53), (34%, compared to 41% Arm 1), and more likely to say it was **good** (17%, compared to 13%)

Less likely to think their GP was **given enough information** about their condition and hospital treatment (question 54), (82%, compared to 91% Arm 1) and more likely to think this was **not the case** (18%, compared to 9% Arm 1)

Less likely to think GPs and nurses at their general practice **definitely** did everything to support them during their treatment (question 55), (38%, compared to 48% Arm 1) and more likely to think they **could have done more** (13%, compared to 9% Arm 1), or that their GP practice was of **no help** (23%, compared to 16% Arm 1)

Less likely to not **want/need support** from the GPs and nurses at their GP practice (question 55), (9%, compared to 13% Arm 1)

More likely to have experienced **moderate pain** during their bone marrow procedure (question 63), (41%, compared to 36% Arm 1) and less likely to say there was **mild pain** (25%, compared to 31%)

More likely to have considered it **positive** if a treatment plan contained a treatment-free period or included stopping treatment altogether (question 65), (70%, compared to 53% Arm 1)

Less likely to prefer to be treated as an inpatient (question 66), (14%,compared to 19% Arm 1) or **outpatient** (58%, compared to 64% Arm 1), and more likely to want to be treated **at home** (28%, compared to 18% Arm 1)

More likely to prefer their treatment to be delivered as an **oral tablet** (question 67), (61%, compared to 57% Arm 1) and less likely to prefer **intravenous infusion** (30%, compared to 44% Arm 1)

More likely to like a **choice of different treatment options** (question 69), (85%, compared to 74% Arm 1)

More likely to consider the following features of a new treatment to be important (question 70):

- **Bring about a remission/response** 60%, compared to 55% Arm 1
- **Improved quality of life** 72%, compared to 67% Arm 1
- **Tolerable side effects whilst on treatment** 62%, compared to 52% Arm 1

- **Certainty of available treatment data/results** 34%, compared to 29% Arm 1
- **Reduced long term effects post treatment e.g. impact on fertility** 26%, compared to 20% Arm 1

Less likely to consider the following features of a new treatment to be important (question 70):

- **Improved blood counts/test results** 52%, compared to 56% Arm 1
- **A reduced impact on carer/family members** 37%, compared to 35% Arm 1

Less likely to think there are enough treatment options currently available on the NHS (question 71), (56%, compared to 74% Arm 1)

Less likely to consider it positive if a treatment would subsequently enable a stem cell transplant (question 72), (79%, compared to 85% Arm 1)

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