



**Blood
Cancer
Alliance**

The unmet needs of people with blood cancer across the United Kingdom

**A review of existing evidence
2022**

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Introduction

Aim

The Blood Cancer Alliance commissioned this report to enable a greater understanding around the key unmet needs of people with blood cancer, particularly when compared to people with other types of cancer. The term ‘unmet need’ can be defined as a deficiency in any areas of a patient’s life that arises as a result of cancer or another chronic ailment.

Approach

As the first step, to identify the main domains of unmet needs within blood cancer patients in the UK, a literature review was conducted. Key search terms were established in cooperation with the BCA member representatives, with an initial scope of: published no earlier than 2015, UK based, and including data related to blood cancer. A key finding was that, while there is recent (2015 onwards) literature examining the unmet needs of blood cancer patients, studies examining the specific needs of UK patients are limited. This area has been the focus of past research but, with developments in the UK health system and advances in treatment, particularly in light of the pandemic, a case could be made that it would benefit from being revisited. While there were non-UK articles which were applicable to an extent, it cannot be assumed that the experiences of patients in other countries will be the same as those in the UK.

Notable unmet needs were identified within the domains of psychological needs, informational needs and treatment journey needs. Also of note, but to a slightly lesser extent, were physical needs, financial needs and needs of adolescent and young adult patients. This report organises information around unmet needs under chapter headings based on the domains identified above. Where possible, the chapters first establish what the needs are before going on to address where there is evidence that they are not met. However, there is overlap and interaction between the chapters. For example, information needs interact with all the other areas, and financial needs are related to experiences within the physical and healthcare journey domains.

The findings from the literature review were mapped against UK Cancer Patient Experience Surveys, BCA member surveys and UK data from global blood cancer surveys. This exercise enriched the literature review findings, as many of these surveys are more recent and include data by specific blood cancer type and UK countries. Where there were gaps in the literature, an approach was taken to include data from studies beyond the scope of the review (such as papers written prior to 2015 or non-UK based) as long as the findings could be similarly evidenced in UK surveys.

Key Documents

In addition to the cited papers this report uses data from fourteen key surveys.

Cancer Patient Experience Surveys (CPES)

Wales 2016 CPES

Northern Ireland 2018 CPES

Scotland 2018 CPES

England 2019 CPES

Blood Cancer Alliance Member Surveys

Lymphoma Action (LA) 2016 Patient Experience Survey

Leukaemia Care (LC) 2016 Patient Experience Survey

Leukaemia Care (LC) 2017 Patient Experience Survey

Blood Cancer UK (BCUK) 2019 Patient Experience Survey

Blood Cancer UK (BCUK) 2020 COVID-19 Patient Experience Survey

Leukaemia Care (LC) 2020 COVID-19 CLL Patient Experience Survey

Leukaemia UK (LUK) 2021 Leukaemia UK Supporters and Beneficiaries Survey

Global Blood Cancer Organisations' Surveys

CML Advocates Network (CMLAN) 2017 Treatment-free Remission Survey - UK data

Acute Leukemia Advocates Network (ALAN) 2019 Quality of Life Survey - UK data

Lymphoma Coalition (LyC) Global Patient Survey 2020 - UK data

Acronyms

ALL	Acute lymphocytic leukaemia
ALLO	Allograft transplant
AML	Acute myeloid leukaemia
ALAN	Acute Leukemia Advocates Network
AUTO	Autologous transplant
AYA	Adolescent and young adults
BCA	Blood Cancer Alliance
BCUK	Blood Cancer UK
CLL	Chronic lymphocytic leukaemia
CML	Chronic myeloid leukaemia
CMLAN	CML Advocates Network
CPES	Cancer Patient Experience Survey
HCT	Hematopoietic cell transplant
HL	Hodgkin's lymphoma
LA	Lymphoma Action
LC	Leukaemia Care
LyC	Lymphoma Coalition
NHL	Non-Hodgkin's lymphoma
NICE	National Institute for Health and Care Excellence
Q	Question
SCT	Stem cell transplant
TFR	Treatment-free remission
TKIs	Tyrosine kinase inhibitors
TYA	Teenagers and young adults

1. Psychological Needs

1.1 Psychological impact of a blood cancer diagnosis

Unmet psychological needs in blood cancer have been well established in existing literature, and are arguably the most prevalent type of need: *Across studies, most common unmet needs are psychological in nature* Barata et al.(1) supported by Swash et al.(2).

But what are the specific psychological issues that blood cancer patients are currently experiencing in the UK and to what extent are their needs in these areas being met?

Depression and anxiety were frequently cited issues, with fear of recurrence, fear of disease progression and concerns for friends and family also being discussed (1-3). It should be considered that all these issues are closely related and interlinked. It could even be argued that fear of recurrence/disease progression and concerns for friends and family are specific examples that come under the broader umbrella of anxiety, and these in turn can feed into feelings of depression. However, as many studies and evaluation tools consider these items separately, we have done the same in this report.

1.1.1 Anxiety and depression

Some older studies in countries outside the UK describe haematological cancer patients as having higher levels of psychological issues compared to common cancer types. 27-48% of haematological cancer patients reported symptoms of anxiety, and 17-38% reported symptoms of depression(4).

Within a recent UK study (5) 50% of patients reported concerns relating to their psychological well-being.

In the results from the LC 2017 survey, between 36-57% of leukaemia patients reported feeling depressed or anxious more often since their diagnosis, depending on their leukaemia type.

LC 2017 Q39. Overall, how has your emotional well-being changed since your diagnosis - **I have felt depressed or anxious more often since my diagnosis**

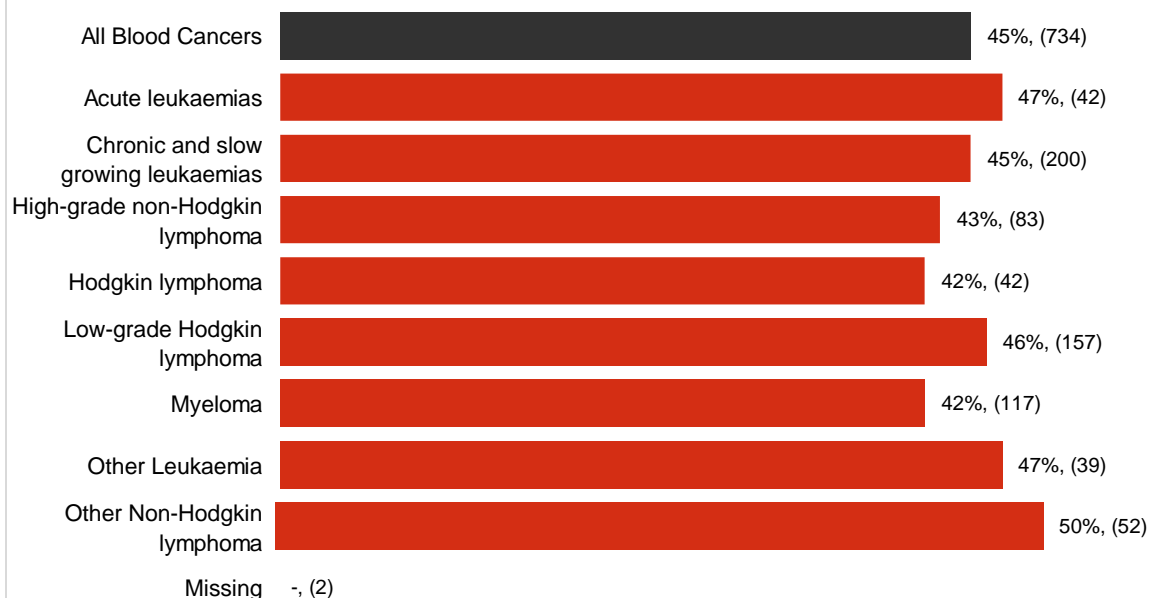


Based on 2271 responses

In the results of the ALAN 2019 survey, on average, 51% of patients reported feelings of depression and 53% reported feelings of anxiety. Furthermore, 19% of respondents said they have been diagnosed with depression since their diagnosis of acute leukaemia, and 27% said they have been diagnosed with anxiety since their diagnosis.

Within the BCUK 2019 patient survey, 45% of respondents said they felt anxious following their diagnosis. In addition, only a quarter of respondents said their diagnosis and treatment of blood cancer had **not** negatively affected their overall mental health / emotional wellbeing at all.

BCUK Q16. Which negative emotions most closely describe how you felt following your diagnosis - **Anxious**



Based on 1634 responses

Within the UK respondents from the LyC 2020 survey, 35% of patients experienced anxiety.

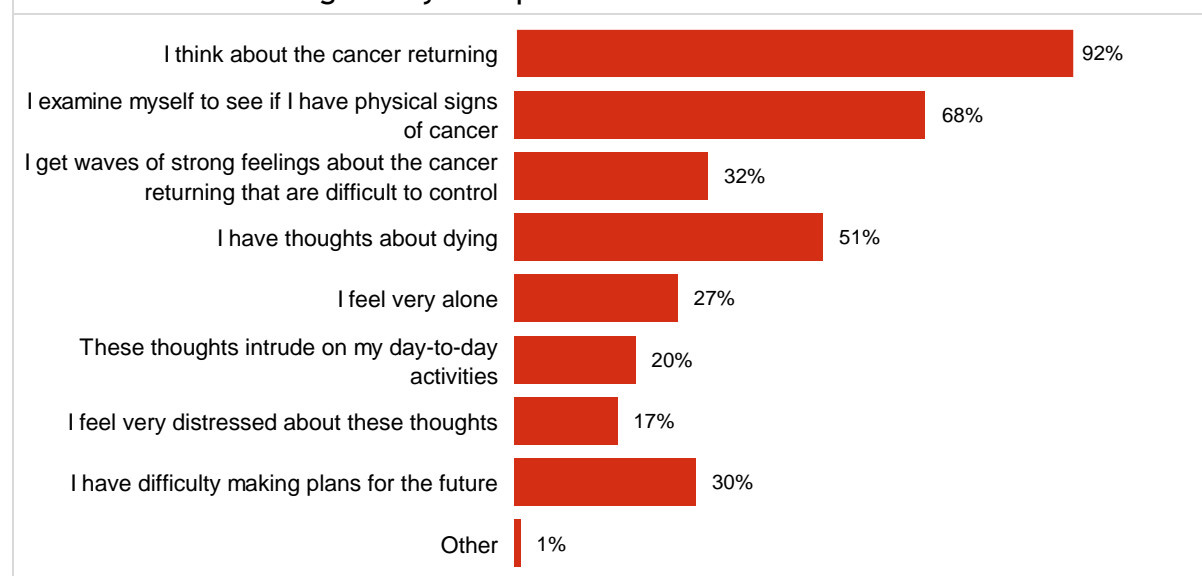
A third of respondents to the LUK 2021 survey reported a large negative impact on their mental or emotional wellbeing in the short term (around diagnosis and treatment).

1.1.2 Fear of disease progression and fear of recurrence

80% of UK respondents to the ALAN 2019 survey reported that they recently had some level of worry that their acute leukaemia would reoccur or that they would relapse. Just over a fifth of respondents said they were very worried.

Within the UK respondents from the LyC 2020 survey, 44% of patients experienced fear of progression of lymphoma and 40% of patients experienced fear of cancer relapse. These were the biggest worries/concerns for patients. Patients who had a fear of relapse also reported a number of other negative psychological experiences.

LyC 2020 Q46. You have indicated that you have experienced a fear of relapse, which of the following have you experienced?



Based on 144 responses

1.1.3 Concerns for friends and family

Within the study by Gosewami et al. (5) 21% of patients discussed worries about their family.

In the UK, over a third (36%) of respondents from the ALAN 2019 survey definitely felt that their disease had an emotional impact on family, friends or carers (FFC) over the last month. Just under a fifth (19%) felt their disease definitely had an impact on FFC social activities and 22% felt it definitely had an impact on the finances of their FFC. When asked to rate the way their acute leukaemia has negatively impacted on the wellbeing and lives of carers, friends and family in the last month, more than a quarter of respondents (26%) chose 0-4 out of 10, where 0 was a large negative impact and 10 was no negative impact.

Within the BCUK 2019 survey, 17% of respondents said the emotional impact of their diagnosis has negatively affected their relationships.

Within the LyC 2020 Global Patient Survey's accompanying caregiver survey, filled in predominantly by partners and family members of someone with lymphoma, 90% of respondents reported being affected by fear of cancer relapse and 89% reported feeling worried and/or anxious. When asked which areas of their life have been impacted most by caring for or supporting someone, the most common response (88%) was emotional.

1.2 Psychological unmet needs

While it is important to understand the context and prevalence of psychological issues in blood cancer patients, there is a clear difference between patients experiencing them, and whether they constitute an unmet need. It should also be considered that the causality between the issues and unmet needs can work both ways; that a psychological issue can be unsupported, but also, from a need unmet or support not given, a psychological need can manifest.

Our literature search revealed a number of studies or systematic study reviews focussing on unmet needs that covered haematological cancers, however most of these were published beyond our search criteria of 2015 or were not UK focussed. This does not appear to have changed significantly since the Improving Outcomes in Haematological Cancers NICE manual (6) was first published in 2003: *"There appear to be few high-quality research studies focusing on non-medical issues or psychosocial interventions for patients with haematological cancers"*. It is crucial that in order to see if progress and change is happening, we need current UK data, but this does not seem to be available.

There is a distinct lack of scientific studies looking at unmet psychological needs in the UK within the last 5-6 years. We have to refer back to older studies and include those from outside the UK to find scientific data on unmet needs in relation to anxiety and depression. There is also less data for individual blood cancers and gaps across the different types.

Evidence of unmet needs

In their 2015 paper Boyes et al.(3) reported on the unmet needs of 311 haematological cancer patients recruited from three comprehensive cancer treatment centres in Australia. They found that 35% of respondents reported a moderate to high unmet need within the psychological domain, furthermore the following individual items were all in the top 10 reported moderate to high unmet needs:

- Uncertainty about the future - 21% (No.3)
- Concerns about the worries of those closest to you - 19% (No.4)
- Fears about the cancer spreading - 17% (No.6)
- Anxiety - 12% (No.10)

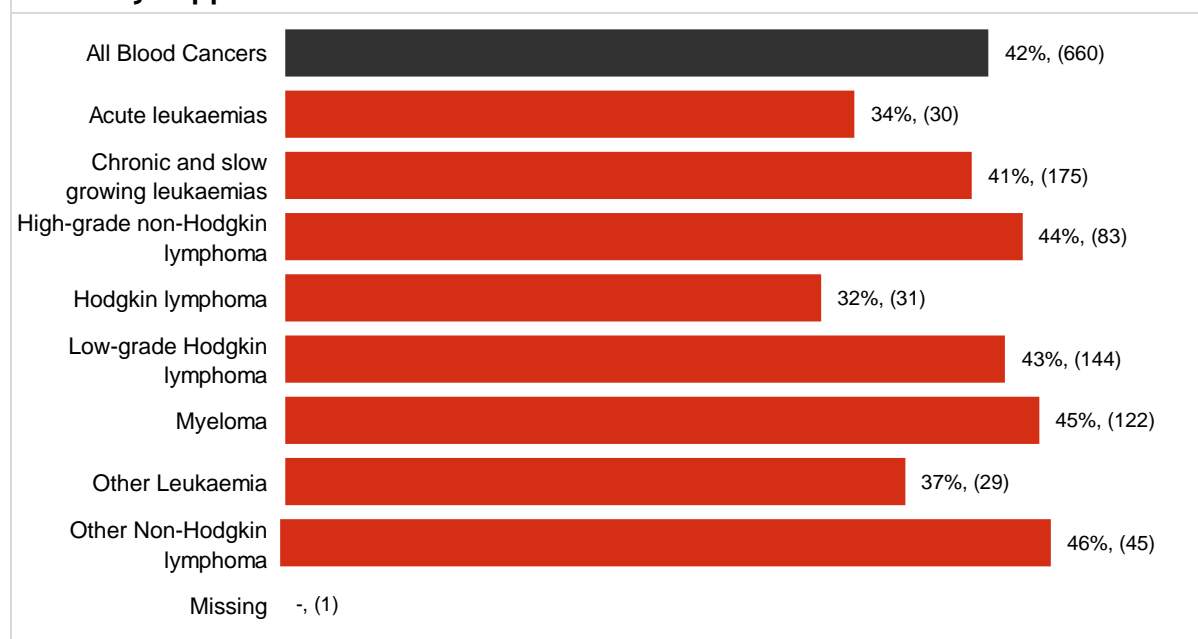
Results from the more recent 2017 UK study (2) of 91 leukaemia and lymphoma patients reported high unmet needs on the individual items:

- Uncertainty about the future -12.1%
- Concerns about the worries of those close to you -12.1%
- Anxiety and fears about the cancer spreading - 9.9%

The lower percentages for those reporting unmet needs compared to experiencing psychological issues can be explained by considering that not all patients that report issues actually want help to manage these feelings. Findings from the study by Swash et al.(2) showed that more participants were anxious than indicated an unmet support need for help to address their anxiety.

Studies by BCA members also show this to be the case. In the BCUK 2019 Survey 42% of respondents said that they had not needed any professional support for their mental health / emotional wellbeing at any point since their diagnosis, although this varied between disease types.

BCUK 2019 Q25. Do you think you have needed professional support for your mental health / emotional well-being at any point since diagnosis? - No, I did not need any support



Based on 1634 responses

However, this does not mean that these unmet needs should not be addressed; especially since the presence of anxiety, depression and a poor quality of life in cancer patients have all been found to negatively impact upon a variety of treatment outcomes such as adherence to treatment, motivation, ability to cope with the diagnosis and on prognosis (7).

It can be contended that all patients should have their need for psychological support addressed by a health professional, even if the patient ultimately decides that no further action is needed.

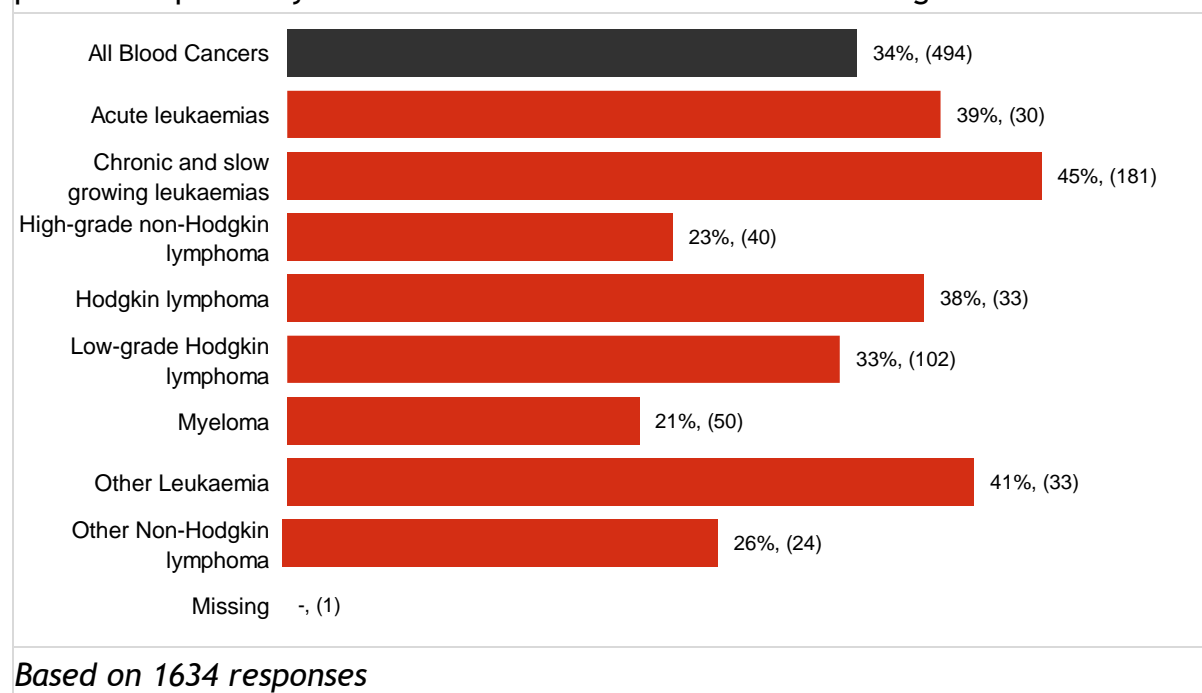
NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer (8), states that: *Psychological distress is common among people affected by cancer and is an understandable response to a traumatic and threatening experience. Patients draw on their own inner resources to help them to cope and many derive emotional support from family and friends. Some patients, however, are likely to benefit from additional professional intervention because of the level and nature of their distress. In practice, psychological symptoms are often not identified and patients lack sufficient access to psychological support services.* This is followed by Key Recommendation 9: *Commissioners and providers of cancer services, working through Cancer Networks, should ensure that all patients undergo systematic psychological assessment at key points and have access to appropriate psychological support. A four-level model of professional psychological assessment and intervention is suggested to achieve this.*

This recommendation refers to another pertinent point, which is that psychological needs can change along the patient journey. This is addressed in the next section: Specific areas that impact psychological unmet needs.

In addition to signifying to clinicians where patients may benefit from further support, an unmet needs assessment also provides an indication of where and with what the patient would like to receive support, thus helping to ensure that resources are allocated to both the area of greatest need but also where they are most likely to be accepted by the patient. It, nonetheless, remains important that clinicians are aware of the on-going potential for distress in patients who do not report a desire for formal support at that time. (2)

When asked what forms of support were the most useful, the most popular answer was written / multimedia information about the possible impact of coping (more than charity support line, support groups and buddy schemes.) Yet, despite the evidence that anxiety and depression are not uncommon among people with blood cancer, more than a third (34%) of respondents to the BCUK 2019 survey said they did not receive any information at diagnosis about the possible impact on their mental health and emotional wellbeing.

BCUK 2019 Q19. When you received your diagnosis, did the healthcare professional offer you information (written, verbal or otherwise) about the possible impact on your mental health and emotional wellbeing? - **No**

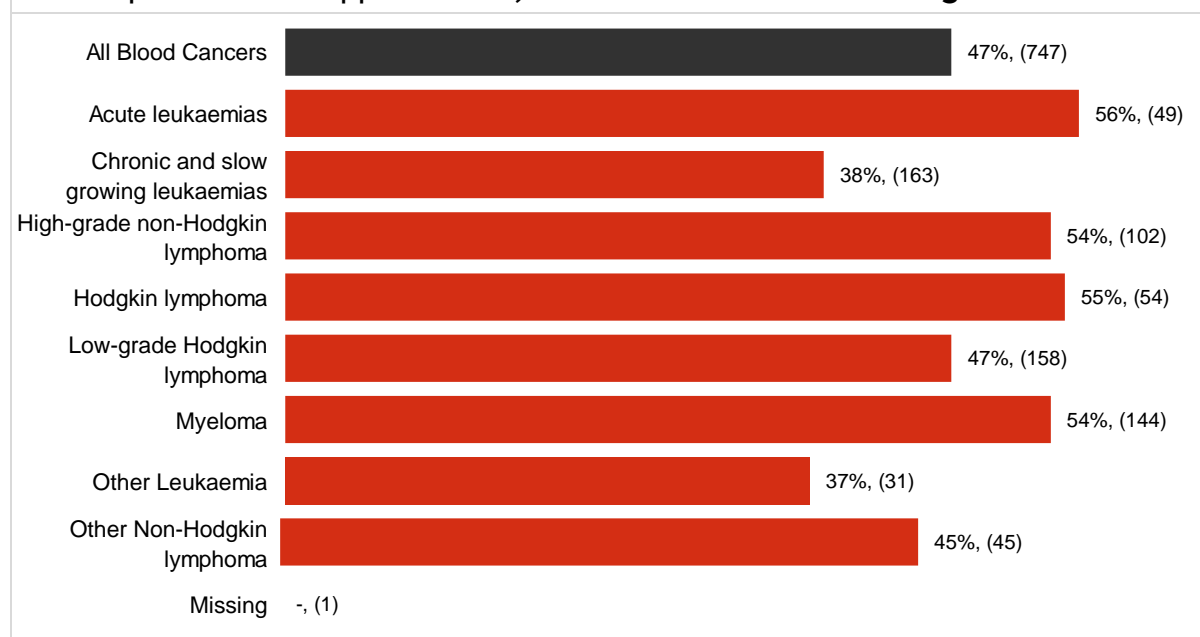


38% of UK respondents to the LyC 2020 survey said they needed more information about psychological support / counselling. Of the patients who said that they discussed depression or anxiety with their doctor around a quarter (depression = 25%, anxiety = 26%) said their doctor wasn't able to help.

Within results from BCUK 2019, less than half (47%) of all respondents were offered professional (emotional) support at any point during their care pathway without asking. Results were most positive for acute leukaemias, high-grade non-Hodgkin lymphoma and Hodgkin lymphoma, with other chronic and other leukaemia having the lowest scores.

Of those who received professional support on the NHS, a fifth said they were not offered enough sessions. Of those who accessed professional support, the vast majority (77%) found it helpful.

BCUK 2019 Q27. At any point during your diagnosis and care pathway were you offered professional support? - Yes, I was offered without asking



Based on 1634 responses

21% of respondents to the ALAN 2019 survey said in the last month their acute leukaemia healthcare team have not given them enough opportunity to discuss the emotional impact of their disease and treatment, but they would have liked this. The same number said they have not received appropriate support from their acute leukaemia healthcare team to manage the emotional impact of their disease and treatment, but they would have liked this, and their healthcare team has not directed them to, or provided them with, information about emotional support, but they would have liked this.

Of the UK respondents to the LyC survey2020 who said that they had a fear of cancer relapse, 46% said that they had discussed their fear of relapse with their doctor. Furthermore, of those who had a discussion only 24% reported that their doctor was definitely able to help and only 21% said that their doctor definitely followed up with them about it.

In the Gosewami et. al qualitative study of 129 patients (5) *“not a single patient mentioned that they were offered any psychosocial screening and/or rehabilitation”*

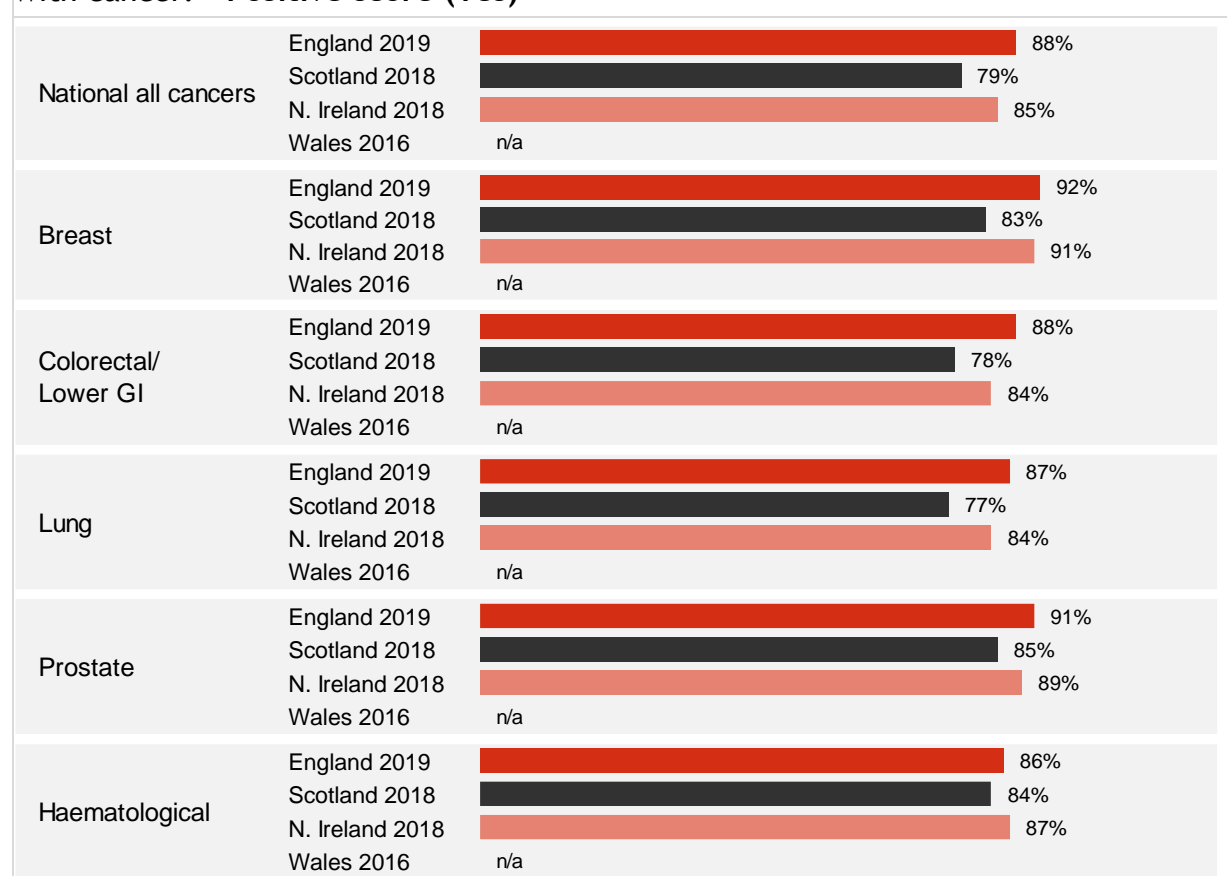
Within the England 2019 CPES, when asked if hospital staff gave information about support or self-help groups for people with cancer, the haematological score was significantly lower than the all-cancer average, as well as below the “big four”.

England 2019 CPES Q22. Did hospital staff give you information about support or self-help groups for people with cancer? - Positive score (Yes)



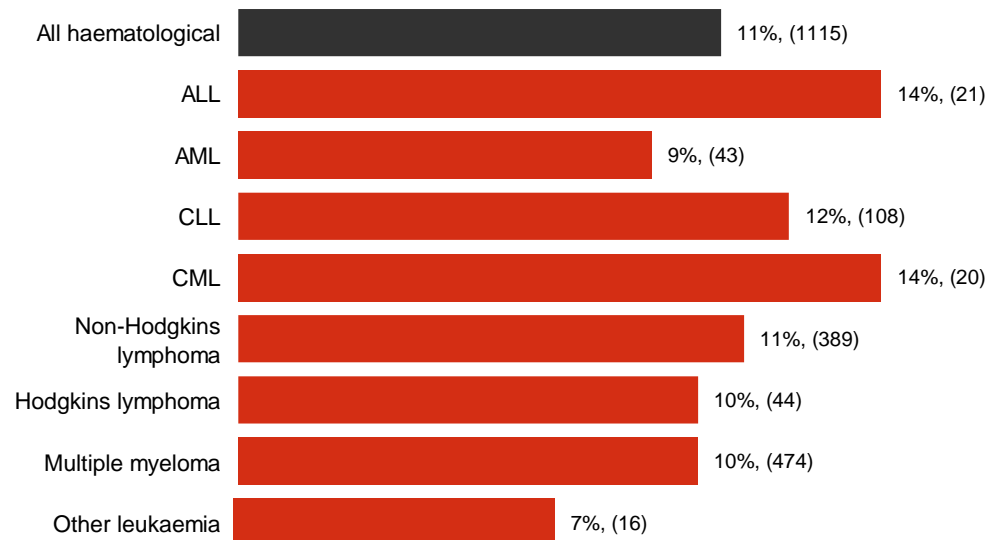
The following chart illustrates how the scores compared across the most recent iterations of CPES across England, Scotland, Northern Ireland.

Did hospital staff give you information about support or self-help groups for people with cancer? - Positive score (Yes)



Overall, 11% (1,115) of haematological patients from England 2019 CPES said that they were not given information about support or self-help groups for people with cancer, but would have liked to have been. There was some variation across different blood cancer types.

England 2019 CPES Q22. Did hospital staff give you information about support or self-help groups for people with cancer? - No, but I would have liked information



Based on 10,579 responses

1.3 Specific areas that impact psychological unmet needs

The occurrence of psychological issues within cancer is not one size fits all, with many different factors influencing the level to which patients experience these. This is particularly pertinent within haematological cancers as this ‘tumour group’ encompasses multiple disease types that vary in aggression, progression, prognosis and treatment, notwithstanding their occurrence in different demographic groups. This next section describes individual factors that have their own psychological impact and unmet needs.

1.3.1 Sensitivity of diagnosis

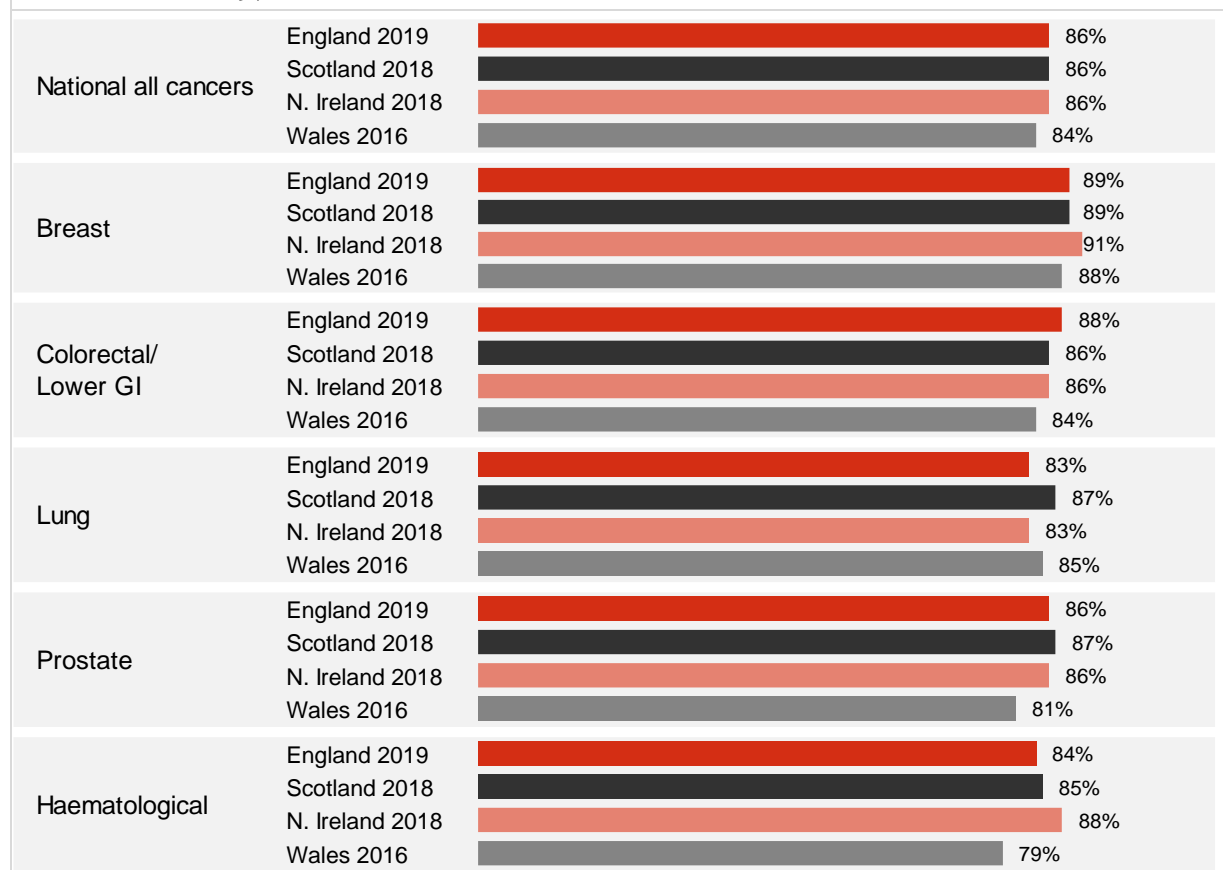
NICE guidance (6) states: *The consultation at which patients learn that they have cancer is a crucial event. Sensitive and compassionate communication is essential. This is, literally, a life-changing experience for patients. Although factual details may be forgotten, the way the news that they have cancer is broken is often remembered with great clarity; it colours later relationships with health professionals, establishing either trust or deep resentment.*

This is echoed within the results from Swash et al. (9) that provides evidence that an initial delivery of a cancer diagnosis is important within the psychological domain: *The initial delivery of the diagnosis was felt to be important and had a real impact on how participants perceived their situation where conversations around diagnosis were felt to be less sensitive than would be desired.*

Evidence of unmet needs

Sensitivity of diagnosis delivery is measured in all UK iterations of CPES. The haematological score for sensitivity of diagnosis¹ ranges from 79% (Wales 2016) to 88% (Northern Ireland 2018). With the exception of Northern Ireland, all haematological scores for sensitivity of diagnosis are below the all cancers average (England sig below). The haematological scores were also below those of breast, colorectal/lower G.I and prostate.

How do you feel about the way you were told you had cancer? - Positive score (It was done sensitively)



Within the BCUK 2019 survey less than two thirds of respondents (62%) said that their clinician was definitely sensitive to their emotional needs when they were diagnosed. 25% agreed to some extent and 13% disagreed entirely.

This data indicates that there are still patients with a haematological cancer who do not have their right to a sensitive diagnosis met, and there remains improvement to be made in the delivery and consideration of emotional impact at diagnosis delivery.

¹ Patients saying that the way they were told they had cancer was done sensitively

1.3.2 Length of time to diagnosis

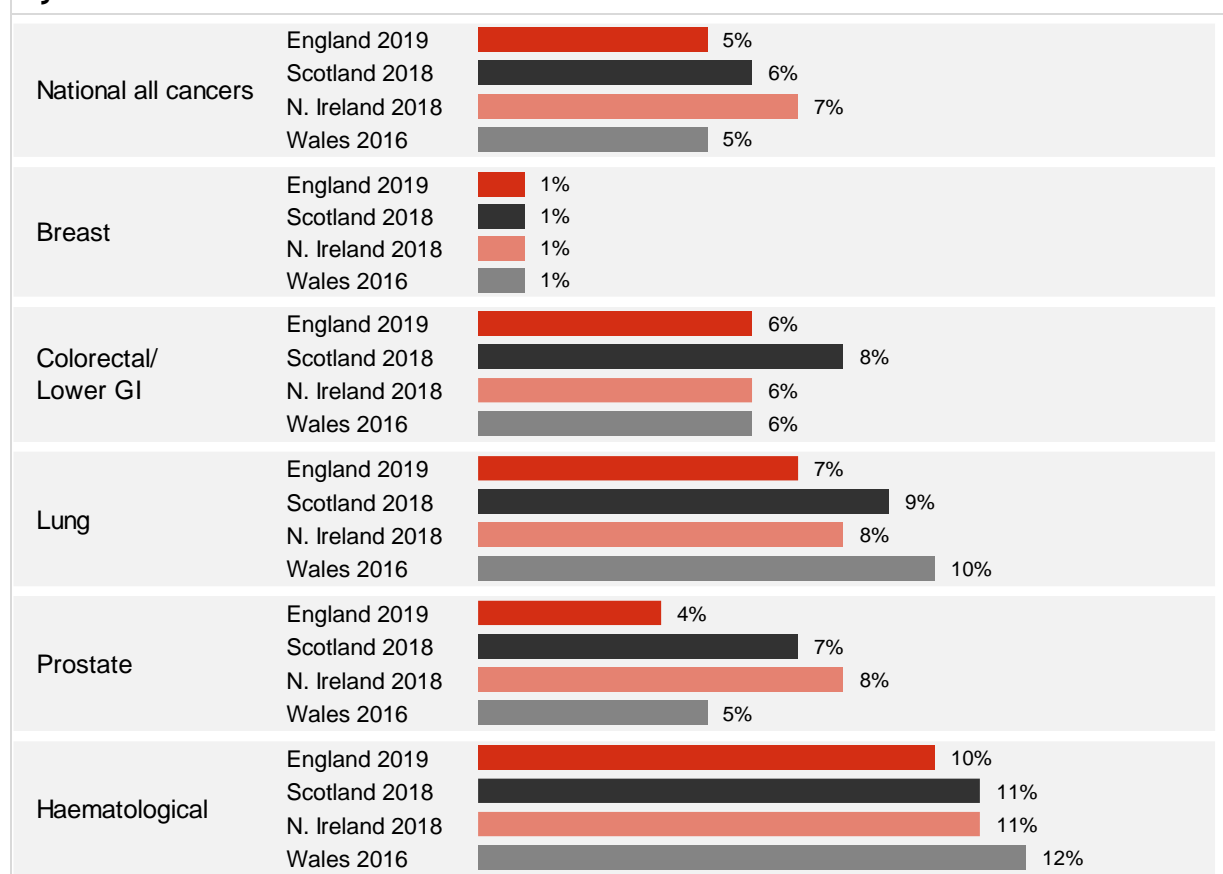
It has been established that a delayed diagnosis can have a negative impact on the clinical outcomes of a cancer diagnosis. However, there is evidence to suggest that the need for reduced diagnosis times should also be considered in relation to the psychological impact on haematological cancer patients.

In the BCUK 2019 survey, more than a third (37%) of respondents said that the length of time to be diagnosed exacerbated worries and concerns about their mental health.

Evidence of unmet needs

Data from the most recent CPES surveys carried out in the UK show that between 10-13% of respondents with haematological cancers had to go to their GP five or more times before they were referred to hospital. These percentages are higher than any of the “big four” across all the surveys.

Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problems caused by cancer? - I saw my GP 5 or more times



When asked how they feel about the length of time they had to wait before their first appointment with a hospital doctor the haematological scores were:

- Significantly below the “all cancers“ score, and also below those of breast, colorectal/lower G.I and prostate - England CPES 2019
- Below the “all cancers score” and had a lower score than any of the “big four” - Scotland CPES
- Slightly higher than the all “cancers” score, and only lower than the breast score - Northern Ireland 2018
- Less positive than the “all cancers” score, and also below those of breast, lung and prostate - 2015 Wales CPES

How do you feel about the length of time you had to wait before your first appointment with a hospital doctor - **Positive score (I was seen as soon as I thought was necessary)**



1.3.3. Watch and wait

Active surveillance, often referred to as “Watch and Wait” is the process of regularly monitoring the blood cancer over time, and only starting treatment when it is necessary. Watch and Wait is used for chronic blood cancers where patients have: *few or no worrying symptoms, whose quality of life and prognosis won’t be affected by delaying treatment* (BCUK). Some of the main blood cancers that are “treated” with Watch and Wait are:

- Chronic lymphocytic leukaemia (CLL)
- Follicular lymphoma
- Asymptomatic (or 'smouldering') myeloma
- Myelodysplastic syndromes (MDS)
- Essential thrombocythemia (ET)
- Myelofibrosis

Anecdotal evidence from patients has described the anxiety caused by being placed on Watch and Wait, so much so, that some patients use the term “Watch and Worry”.

Our literature review did not find any relevant articles that dealt with patient experience and unmet needs within active surveillance for haematological malignancies. The papers we found on this topic only covered Watch and Wait within prostate cancer.

There are also limitations for patient experience data from people on Watch and Wait as they are not fully captured in the National Cancer Patient Experience Surveys. The sample for these surveys capture patients who have been admitted to hospital as an inpatient for cancer related treatment, or who were seen as a day case patient for cancer related treatment, so Watch and Wait patients are not well represented.

However, the LA 2016 survey, LC 2016 and 2017 surveys all included questions asking about the experiences of patients on Watch and Wait.

BCUK ran an online opt-in survey in 2019 for people on Watch and Wait, alongside the targeted CPES follow-on cohort. Breaking down the results into the CPES and Watch and Wait cohorts should be done cautiously, as there were only 204 respondents to the Watch and Wait online survey, but the results are worth looking at nonetheless.

- Over half of patients put on Watch and Wait had concerns or worries about it. (LC 2017 and LA 2016).
- Only around a quarter (26%) of Watch and Wait respondents didn't think they needed professional support for their mental health / emotional wellbeing at any point since diagnosis. (BCUK 2019)
- When asked what information is most important at diagnosis (excluding options about treatment and Watch and Wait), the CPES cohort were most likely to choose practical things you can do to help yourself (48%) while the Watch and Wait cohort were most likely to say information about the emotional impact of blood cancer and where to get support (49%). (BCUK 2019)

Evidence of unmet needs

There is a need for the experiences of Watch and Wait patients to be captured at a National level, so that their psychological unmet needs can be understood.

NICE guidance (10) states that if Watch and Wait is suggested for a patient, that healthcare professionals should address any increased anxiety that results from this approach.

From the results collected by BCUK there appears to be some disparity between the psychological information and support provided to patients who are on Watch and Wait, compared to those who are not:

- 68% of the Watch and Wait respondents said they were not offered any information at diagnosis about the possible impact on their mental health and emotional wellbeing, compared to 29% from the CPES cohort.
- 51% of CPES respondents were offered professional support at some point during their diagnostic and care pathway, whereas only 20% of the Watch and Wait respondents were.

There is a need to address this inequality, ensuring that patients on Watch and Wait are assessed and given appropriate access to information and informal/formal support where it is wanted by the patient.

1.3.5 Treatment

Treatment for blood cancers varies considerably, dependent on the type of cancer, the disease progression and other factors including patient age. Treatments include stem cell transplant, chemotherapy, radiation therapy, immunotherapy and targeted therapy such as tyrosine kinase inhibitors (TKIs).

In the BCUK 2019 survey, when asked when professional support is most needed, the most common answer was during treatment (24%).

Stem cell/Haematopoietic transplants

Studies from other countries (11-15) have shown that stem cell transplant (SCT) survivors experience psychological burden across a number of items:

- Significant depression ranging from 13 to 27%
- Significant anxiety estimated to occur in 14 to 27%
- Significant fear of progression in 23 to 29%
- Post-traumatic stress disorder estimated to range from 15 to 28%

In the BCUK 2019 survey, respondents were asked to what extent has their diagnosis and treatment of blood cancer / care pathway had negatively affected their overall mental health / emotional wellbeing. 81% of respondents who had a stem cell transplant reported a negative effect, compared to 74% who had not had a stem cell transplant. The top three negative emotions SCT patients reported were:

- Feeling anxious (41%)
- Feeling fearful (29%)
- Low mood (21%).

In particular, more people who had a stem cell transplant used the adjective ‘fearful’ to describe how they felt following diagnosis, compared to respondents who had not had a stem cell transplant (29% compared to 22%). Just under a third (31%) of SCT respondents felt they needed professional support for their mental health and emotional wellbeing since diagnosis; the majority of these (36%) felt they needed professional support most during treatment. However, 20% of SCT patients said information about the emotional impact of blood cancer / their condition and where to get support was most important in remission, compared to 7% in treatment.

Evidence of unmet needs

Results from BCUK 2019 survey indicated that at diagnosis, a quarter of SCT patients were not offered information about the possible impact on their mental health and emotional wellbeing. Furthermore, only around half (55%) of SCT respondents were offered professional support unprompted.

Sarkar et.al (12) reported that of allogenic HCT reporting distress, only 39% were taking antidepressant or anxiolytic medications and 22% were receiving psychotherapy.

A study run by Anthony Nolan in collaboration with the British Society for Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT) explored psychological care in 24 UK allograft transplant centres (16). Results illustrated that psychological care is variable within the 24 UK centres, and there are areas which are not well served.

Workforce

Only a third (8/24) of the transplant centres have a psychological practitioner based within the haematology service and only 4 centres have them embedded in the transplant team. Only around half of centres 11/21 carry out training of the transplant team members on psychological care skills.

Identifying issues

Just under half (11/23) of centres don’t perform any regular pre-transplant screening for psychological needs, and 12/23 don’t carry out any psychological screening post-transplant. Only just over half 12/21 of centres report having a clear pathway for psychological assessment. 76% of nurses (16/21) rated themselves as confident/very confident that they would be able to identify and refer patients with psychological distress, however only 30% of doctors (6/20) rated themselves as confident/very confident to do the same.

Information

Data from the survey also identifies that the provision of information regarding the psychological impact of transplant is not always communicated to patients within the centres:

- 14/20 (67%) physicians discuss psychological impact of transplants with allograft (ALLO) patients
- 9/20 (45%) physicians discuss psychological impact of transplants with autologous (AUTO) patients
- 15/21 (71%) nurses discuss psychological impact of transplants with ALLO patients
- 15/21 71% nurses discuss psychological impact of transplants with AUTO patients

Key Performance Indicators (KPIs)

KPIs are used by only 52% of centres to assess service quality. In particular:

- Only half (11/21) assess responsiveness of service: Number of working days until specialist appointment is offered
- 38% (8/21) assess responsiveness of service: Number of days following specialist appointment until therapeutic intervention
- 43% (9/21) monitor the percentage of CNS staff who have completed level 2 psychological skills training
- A third (7/21) monitor the percentage of patients who have been offered a Holistic Needs Assessment
- No centres monitor the percentage of patients with a supportive needs care plan

Services

The survey found that “one-to-one specialist services are widely available. However, access to these services is dependent on the overall specialist workforce.” Services less widely available are:

- Additional psycho-educational services - available in 7/21 centres
- Peer led support groups - available in 5/21 centres
- Psychiatry Liaison services - available in 9/21 centres

1.3.6 Treatment free remission

In recent years, Treatment-free Remission (TFR) has become a goal of treatment in CML; wherein patients who achieve a durable deep molecular response can stop taking their TKI treatment and remain drug free. In 2018 the CML Advocates Network ran a global survey to understand the experiences of patients attempting to achieve TFR. The results indicated some particularly compelling findings that related to psychological issues and unmet needs (17).

As TFR is a very new concept, the number of patients participating from the UK was small. 45 patients from the UK participated in the survey because they had considered trying to achieve TFR. 25 actually proceeded to stop treatment, 12 had to restart treatment (following stopping), and 6 were in long term TFR beyond 6 months. The small numbers do limit the robustness of conclusions, but they are reflected in the global data.

- When contemplating whether to discontinue treatment 29% would have liked to have received information on emotional support
- 40% of patients would advise someone considering TFR to get emotional support
- 24% of patients would advise someone considering TFR to get psychological support

During the first 6 months of stopping treatment:

- 33% experienced depressive episodes, fear or bad mood
- 67% experienced some fear or anxiety, mostly around the time of any monitoring tests
- 65% reported that stopping treatment had a positive effect on their emotional well-being
- 50% reported that stopping treatment had a positive effect on family and social relationships

Of the patients that had to restart treatment:

- 82% felt scared or anxious when they were told their disease had reoccurred
- 44% felt depressed
- 67% felt some anxiety

In the global data, late recurrence was a concern for patients in long-term TFR but only a small number of UK patients were in this stage.

Evidence of unmet needs

Discussion on the global data acknowledges that the need for psychological support varies throughout the TFR pathway, but recommends that psychological wellbeing of CML patients attempting TFR should be a consideration of healthcare professionals and form part of routine monitoring (17). UK data supports this:

During the first 6 months

- Just 2 patients discussed with their doctor how to deal with psychological aspects
- 25% didn't receive any type of psychological or emotional support, but would have liked to have done
- 26% said their doctor didn't ask them if they needed psychological support during the stopping of treatment but they would have liked this

Of the patients who had to restart treatment:

- 27% didn't receive any type of psychological or emotional support, but would have to have done

1.3.7 COVID-19

There is limited data relating to the impact COVID-19 has had on the psychological wellbeing of people in the UK who have blood cancer.

A recent study by Gallagher et al. (18) identified that (along with breast and prostate), people living with blood cancer: *appear to be at an increased risk of depression during COVID-19, and that feelings of isolation help explain this risk.* Furthermore, people with blood cancers were more likely to be lonely ‘*more often*’ than other groups, and rates of depression increased over time more than other cancer types.

86% of respondents to the BCUK 2020 COVID-19 survey reported that their mental health / emotional well-being has been impacted to some extent by the pandemic.

Respondents also reported the following negative emotions due to the pandemic:

- 67% feeling anxious
- 46% feeling fearful
- 45% feeling low in mood
- 36% feeling stressed
- 32% feeling lonely / isolated

And in relation to their day-to-day lives:

- 59% said it affected their ability to enjoy life
- 58% said it impacted on their stress / anxiety levels
- 52% said it impacted on their hopes for the future
- 41% said it impacted on their happiness

Just under a third (32%) of patients responding to the LUK 2021 Survey said that the impact of COVID-19 had negatively impacted on their mental wellbeing.

These results are in part supported by an Australian study (19) where 35% of respondents reported elevated levels of distress ranging from mild (17%) to severe (9%).

Within results from a CLL specific survey run by LC in May 2020, 16% of patients said they were not coping well due to ongoing shielding

Evidence of unmet needs

Data relating to unmet psychological needs in the UK is even less available.

Of the respondents within the BCUK COVID-19 survey who were accessing professional support for their mental health prior to the pandemic, 32% of these respondents reported having lost access to this support.

2. Physical Needs

Physical impact

The physical impact of a blood cancer diagnosis affects patients with all types of haematological malignancies. The side effects of treatment vary in severity and longevity, lasting throughout treatment and beyond. This section will summarise some of the physical symptoms and side effects reported in the most recent research and surveys, along with how well these are managed and where there are gaps and unmet needs in regard to management.

2.1 Symptoms and side effects

Blood cancer patients can experience a range of physical symptoms and side effects dependent on disease type. Whilst developing a Quality of Life tool for haematological malignancies, Goswami et al. (5) identified the most prevalent disease side effects as tiredness, feeling unwell, breathlessness, lack of energy, and back pain, and the most prevalent treatment side effects as tiredness, feeling sick, disturbance in sense of taste, and breathlessness.

In the ALAN 2019 survey, the symptoms or side effects most frequently reported by UK respondents as severe were: energy levels (30%), feeling tired (30%), hair loss (24%) and body pain (14%). 39% also reported that they had a lot of difficulty with physical activity and sport. Furthermore, only a quarter of respondents felt they could completely carry out all the physical activities that they could before diagnosis. Of the respondents who felt they couldn't carry out the physical activities as they did before, 35% had a lot of concerns about this.

Within the UK respondents to the LyC 2020 survey, over half of respondents (56%) agreed or strongly agreed that their lymphoma symptoms negatively impact on everyday activities that people their age can usually do. 38% said they have been unable to work or had changed their working pattern because of the side effects.

Over two in five patients (44%) responding to the LUK 2021 Survey reported that blood cancer had a large negative affect on their physical wellbeing around the time of diagnosis and treatment. One in five patients (20%) who had completed treatment were experiencing a large negative impact on their physical wellbeing in the longer term.

Fatigue was the symptom or side effect most frequently cited across the surveys as having a significant impact on the lives of people living with blood cancer. Of the UK respondents to the LyC 2020 survey, over three-quarters of patients chose fatigue as the symptoms of lymphoma/CLL which affects them the most, and the side effect of treatment which affects them the most. 30% of those who experienced fatigue as a result of treatment experienced it for more than 8 years.

Evidence of unmet needs

In a recent Australian study, (3) lack of energy/tiredness was the top most prevalent “moderate to high” unmet supportive care need (24%).

This is echoed by the UK respondents to the ALAN 2020 survey, where it was reported that energy level and tiredness are the physical symptoms/side effects that they would like most help/support with (24%).

In the LyC 2020 survey, 63% of UK patients said that they had discussed their fatigue with their doctor in the last two years. However, 44% reported that their doctor did not take any action after the discussion and almost half (48%) said that their doctor did not follow up with them.

Respondents to the ALAN 2019 survey were predominantly positive about the way their physical symptoms and side effects of acute leukaemia had been managed by their healthcare professionals in the last month, 9% chose 0-4 out of 10, where 0 was a very dissatisfied and 10 was very satisfied. However, of the respondents who felt they needed to discuss physical symptoms and side effects, 20% said this didn’t happen even though they would have liked it. Of those who felt it was necessary for them to receive support to manage their physical symptoms and side effects, 17% didn’t receive it but would have liked it. There were also a quarter of respondents who felt they needed support for physical rehabilitation, but were dissatisfied with what was provided by their hospital or healthcare provider.

62% of the LyC 2020 UK survey respondents discussed their treatment side effects with their doctor, but only 19% said that their doctor was definitely able to help with them.

2.1.2 Adherence and treatment-free remission

The burden of side effects due to treatment in chronic blood cancers is one of the reasons that a patient may not adhere to their medication (20) or may consider treatment-free remission (17).

Over half of UK respondents to the CMLAN 2017 TFR survey (58%) said that one of their main reasons for considering stopping treatment was to get rid of treatment side effects. However, 72% (18) of the patients who proceeded to stop treatment experienced withdrawal symptoms, 94% (17) had pain in muscles, joints or bones, and 72% (13) experienced tiredness.

Evidence of unmet needs

Of those who considered stopping treatment, 56% (25) would have liked to have received information about withdrawal symptoms.

During the first 6 months of stopping treatment:

- 80% (20) did not discuss how to deal with withdrawal symptoms with their doctor.
- 39% (7) were not asked by their doctor or a healthcare professional if they were experiencing withdrawal symptoms, but would like to have been.
- 24% (4) said their doctor completely supported them in managing physical withdrawal effects.

3. Informational Needs

3.1 The need for information

The need for quality information is widely recognised as a key pillar of cancer care. NICE guidance states: *Most patients and carers want information about cancer and its treatment throughout the patient pathway. They expect information to be up-to-date and of high quality.* (8)

While many areas of need are common across different cancer types (21), there is evidence to suggest that haematology patients report feeling different to other cancer patients, perceive their diagnosis to be poorly understood by others (including healthcare professionals) and benefit from non-generic support services (9). In particular, there is benefit to information being considerately managed by practitioners to their individual circumstances (22).

Due to the evidence that there is a higher need for disease and treatment-related information among people with haematological malignancies than psychosocial information (23), in addition to the crossover with psychosocial information as a resolution for other areas of need addressed in this report, this chapter will particularly focus on the former.

3.1.1 Information about disease and treatment

This chapter will particularly focus on information about treatment and disease-related information. NICE guidance recommends that: *patients and carers are offered help to understand information materials, should they so request, to enable them to decide what care options are most appropriate for them* (8).

Receiving more disease-specific information is something that was supported as a preference in the local surveys investigated. In the BCUK 2019 patient survey, when asked what information is most important at diagnosis (other than information about their condition) the most popular responses were side effects of treatment (65%) and practical things you can do to help yourself (46%). These were above options like ‘the emotional impact of blood cancer and where to get support’ (10%), support for family / friends (12%), and dealing with practical issues (7%).

There is evidence that: *receiving more disease-specific information was associated with a better understanding of and control over the disease, and more satisfaction with the information received was associated with better illness perception (23).*

3.1.2 Psychosocial information

Psychosocial information is identified as less of a need among people with haematological malignancies than disease and treatment related information (23-26).

Furthermore, in many cases information (i.e. signposting towards appropriate resources) can be a resolution to unmet needs addressed in other chapters e.g. psychological and financial unmet needs. Therefore, while it will be briefly addressed in this chapter where appropriate, this will largely fall into the other related chapters.

3.1.3 Management, delivery and quality of information

While the provision of information is important, consideration should also be placed on how it is presented to the patient, along with the quantity and quality. Treating clinicians are widely regarded as a patient's most trustworthy source of information, and there is evidence to suggest that how the clinician manages the delivery of information influences how useful the patients finds it, and can even 'make or break' the patient/clinician relationship. Qualitative studies have shown that patients trusting clinicians to select and manage information allowed them to feel informed. Furthermore, these patients are largely content with the information they receive from physicians, however much or little they actually receive, and that that caring relationships with physicians facilitate this contentment. "Patients felt comforted by knowing that practitioners had thought about what information to provide. That is, patients inferred practitioners' caring from how considerately they managed information, just as they might infer caring from how sensitively practitioners conducted a physical procedure." (22).

3.2 Unmet informational needs

While the need for information is well established, the extent to which this need is being met in the UK is less evident in literature. There were a limited number of articles that fell within the original scope of the literature search, and this lack of recent, relevant literature is further evidenced by highly relevant articles often citing substantially older or more less specific literature.

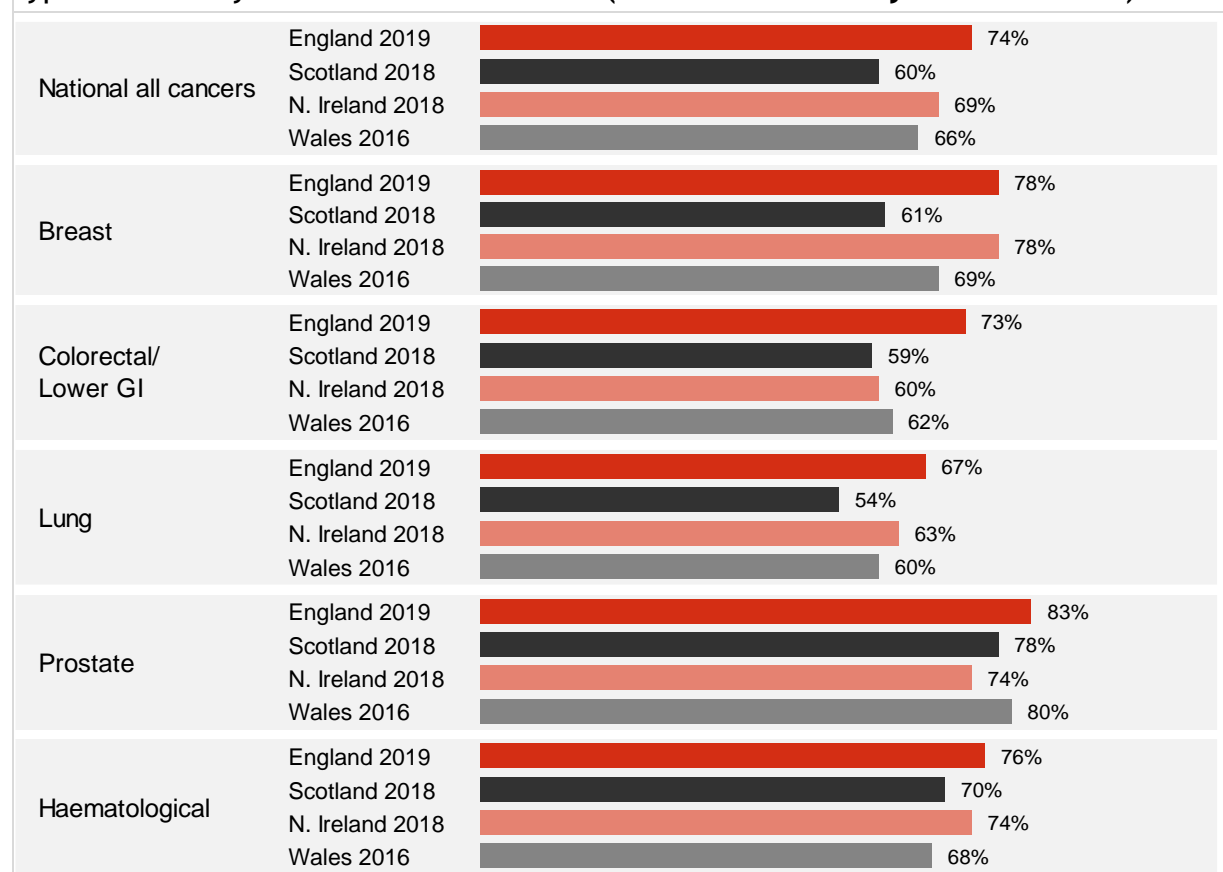
This chapter will go on to consider information that pertains to different stages in the patient journey however, when here referring to informational in the most general sense, this relates to information (and subsequent understanding) around the patient's diagnosis. This differs to information that specifically relates to the diagnostic process / diagnostic period, which is addressed in 3.3.1.

The perceived importance of information from a patient perspective is evident in the number of questions in UK cancer patient experience surveys and local surveys which referenced quality and quantity of information. In the search for general unmet informational needs, there were areas uncovered where needs appear to be met (at least to a reasonable extent):

- 91% of leukaemia respondents to the LC 2017 patient survey rated the information they were given by charities as good, very good or excellent.
- 40% of UK respondents to the ALAN 2019 survey rated information they were given or directed to by healthcare professionals to help them understand and manage their acute leukaemia as 10 out of 10 - the most popular response. 81% rated this information as a 6 or above.

The UK CPES haematology scores for patients being given understandable written information about the type of cancer they had are favourable compared to the “all cancer” averages. However, there are still between a third and quarter of haematology patients who do not fall into this category.

When you were told you had cancer, were you given written information about the type of cancer you had? - **Positive score (Yes and it was easy to understand)**



While these scores perform slightly better than some other cancers, they are outweighed by areas where a substantial portion of survey respondents, and in the case of CPES often more than other tumour groups, reported not receiving the information that was needed.

Evidence of unmet needs

48% of respondents to the BCUK 2019 survey said that at no point has a healthcare professional directed them to a charity for their information and support needs.

8% of leukaemia respondents to the LC 2017 survey said hospital staff did not give them information for people with blood cancer, but they would have liked this. 89% were given information on blood cancer, 60% practical information and information on emotional support.

8% of UK respondents to the ALAN 2019 survey said their acute leukaemia healthcare team have never directed them to or provided them with information about their disease and treatment, but they would have liked this. The quality of this information is largely rated positively - 87% said good or very good. 28% of people said the information is somewhat easy to understand and they understand some of it.

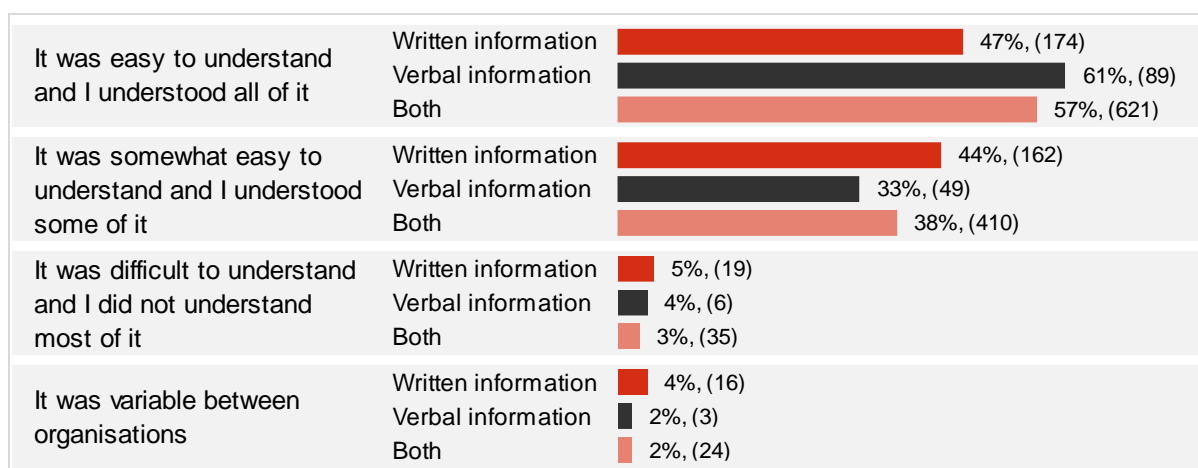
Atherton et al. (27) reflect that unmet information needs could be markers of difficulties in the patient/clinician relationship rather than a problem to be solved by the provision of additional information.

While research and policy literature on patients' information needs in cancer typically refers to information as a 'quantity' and 'how much' information patients want about different topics, research by Atherton et al. (22) offer an alternative perspective: "Our participants' accounts indicated the limitations of this unidimensional view which disregards the different ways in which information can be conveyed". Results from this qualitative study showed that patients valued clinicians use of visual representations to simplify information for example, graphs that made sense of treatment decisions.

Different ways of delivering information can be beneficial, particularly where written information can use "unfriendly" language.

This can be evidenced by results from the LC 2017 survey, where people who only received written information were less likely to say it was easy to understand compared to those who received information verbally, or both written and verbal information.

LC 2017 Q45. How easy was this information to understand?



Based on 1608 responses

3.3 Specific areas of unmet informational needs

This section will address informational needs at different points in the patient pathway and for different groups, and where these needs are not met in terms of quantity and quality of information delivered.

3.3.1 Diagnostic process

NICE guidance on suspected cancer: recognition and referral (28) recommends that people with suspected cancer are given comprehensive information about the diagnostic process:

The information given to people with suspected cancer and their families and/or carers should cover, among other issues:

- *Where the person is being referred to*
- *How long they will have to wait for the appointment*
- *How to obtain further information about the type of cancer suspected or help before the specialist appointment*
- *What to expect from the service the person will be attending*
- *What type of tests may be carried out, and what will happen during diagnostic procedures*
- *How long it will take to get a diagnosis or test results*
- *Whether they can take someone with them to the appointment*
- *Who to contact if they do not receive confirmation of an appointment*
- *Other sources of support.*

That information is most needed at the point of diagnosis is inconsistent in the literature examined, however the results of the local surveys support the need for quality information during the diagnostic process.

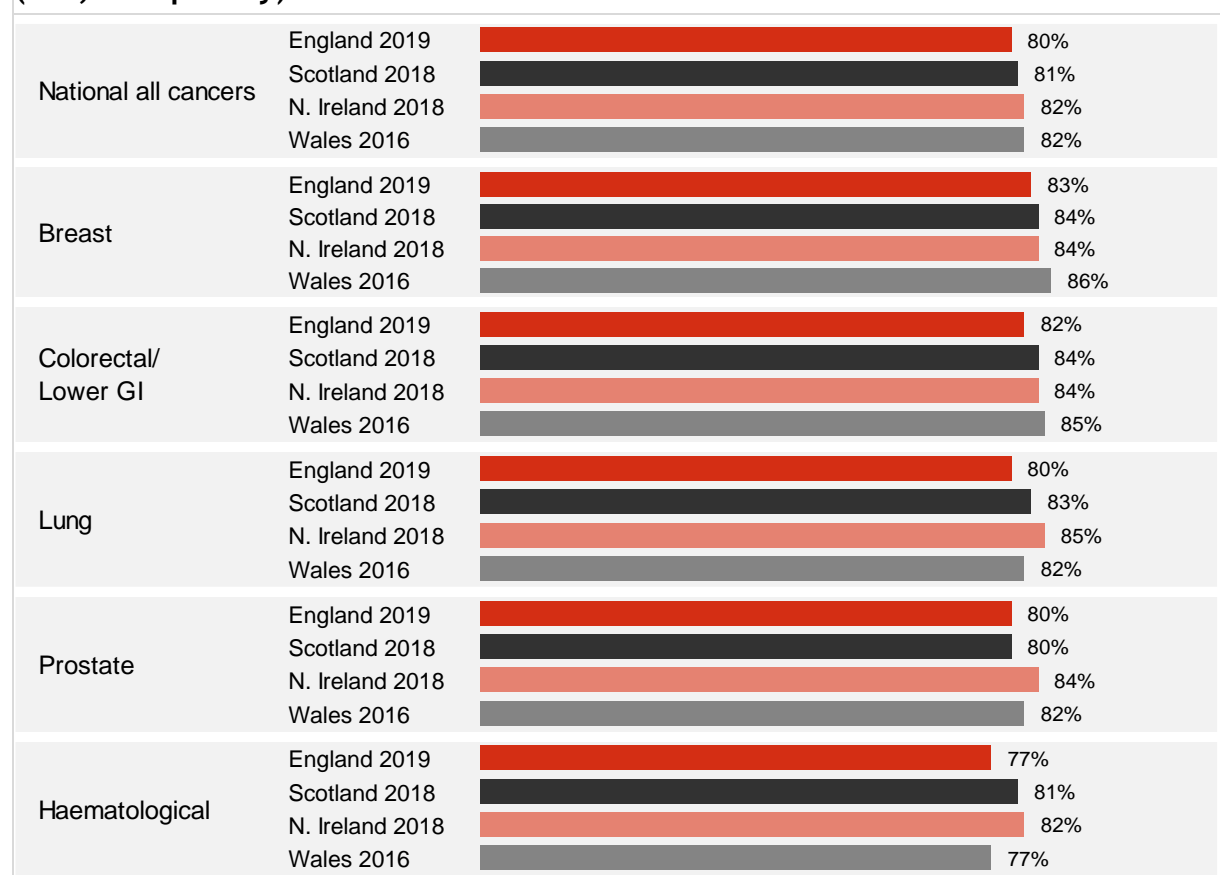
In the BCUK 2019 survey, when asked when they feel they've needed the most information to support them, the most popular responses were at my diagnosis (27%) and soon after my diagnosis (30%).

This is corroborated by the LyC 2020 survey, where 57% of UK respondents had the greatest need for information within the first month of their diagnosis.

Evidence of unmet needs

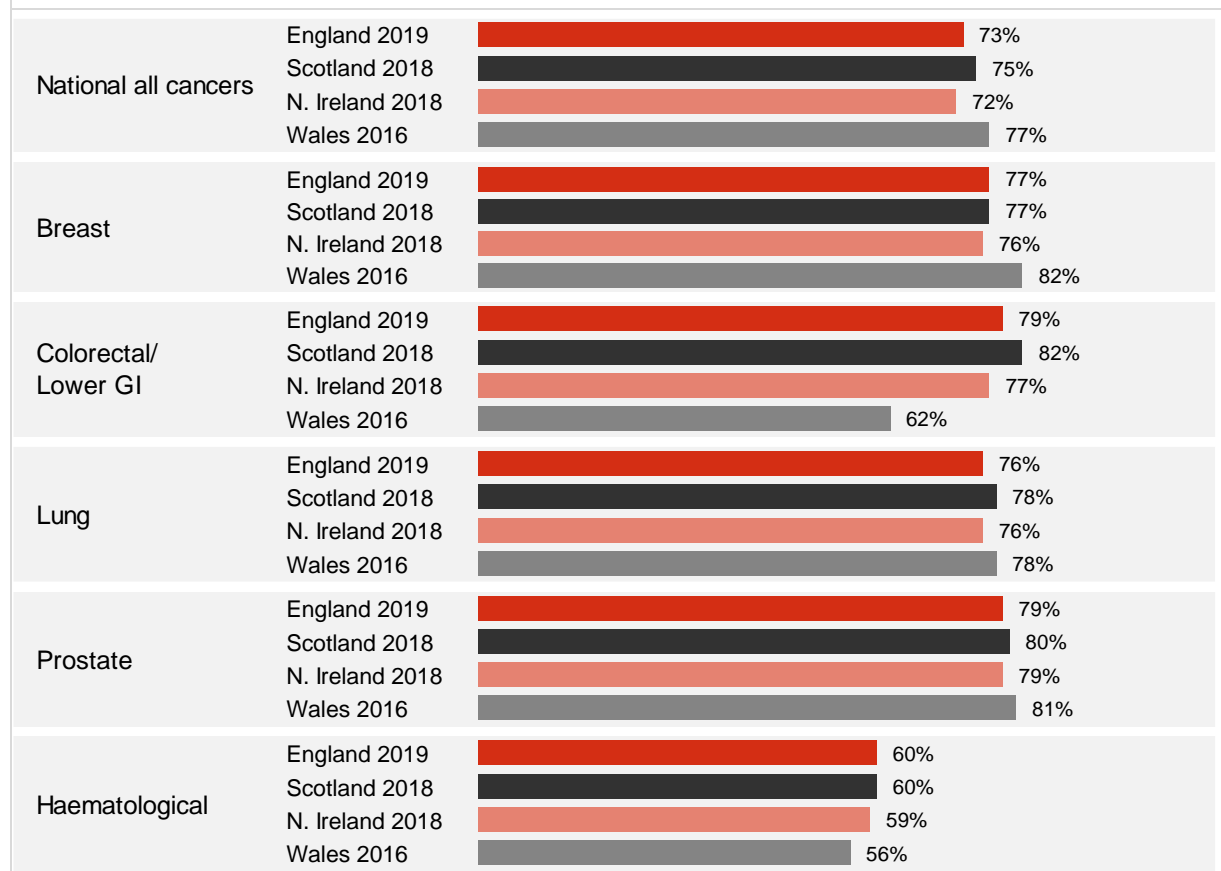
Results from the England 2019 CPES, showed that haematology respondents who had diagnostic tests were significantly less positive that the test results were explained in a way they could understand, when compared to the “all cancers” average. The score was also worse than the “big four”. In the results from the Wales 2016 CPES, the haematology score was lower than all of the “big four”

Were the results of the test explained in a way you can understand? - Positive score (Yes, completely)



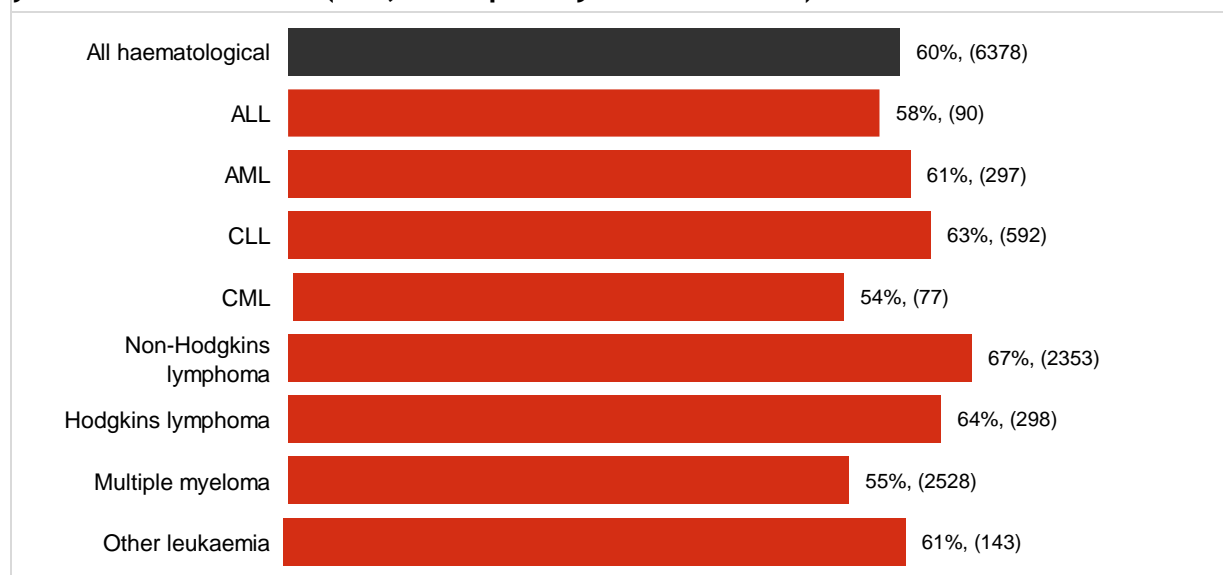
Results from the most recent UK iterations of CPES indicate that there is a need for clearer explanations to be given to haematology patients about what is wrong with them. Across all four CPES surveys, the haematological scores were significantly worse than the “all cancers” average, and lower than scores for the “big four”.

Did you understand the explanation of what was wrong with you? - Positive score (Yes, I completely understood it)



There is further difference between blood cancer type with only around half of CML and multiple myeloma patients completely understanding the explanation.

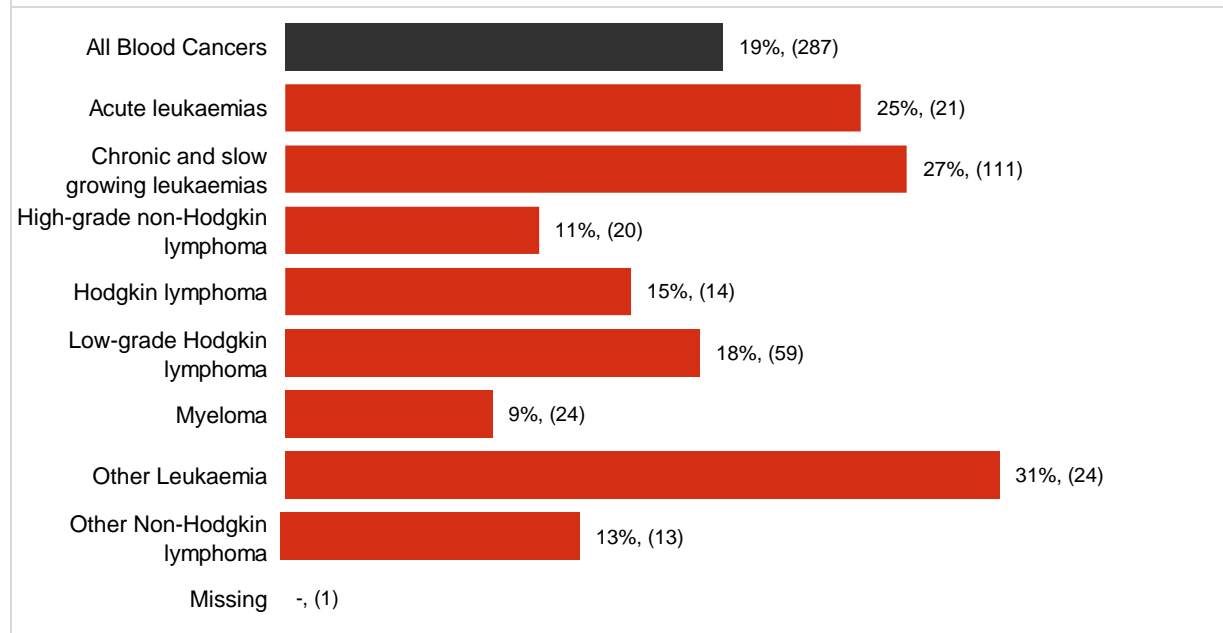
England 2019 CPES Q12 Did you understand the explanation of what was wrong with you? - Positive score (Yes, I completely understood it)



Based on 10,624 responses

19% of respondents to the BCUK 2019 survey said that at diagnosis, they were not given enough information. This ranged between 9-31% across the different disease types.

BCUK 2019 Q55 At diagnosis were you given ...? - Not enough information



Based on 1,525 responses

28% of leukaemia respondents to the LC 2017 survey said that the health professional who gave their diagnosis didn't recommend anything about finding further information.

More than two thirds (69%) of leukaemia respondents to the LC 2017 patient survey said the health professional who gave their diagnosis made no reference to online information or the internet. This is a missed opportunity to direct patients to additional, “good” information, as regardless of what their health professional said, 61% of patients went on to use the internet to find further information. Further analysis of this data showed that patients whose health professional told them to look at trusted websites were significantly more likely to find useful information.

3.3.2 Treatment

NICE guidelines on patient experience in adult NHS services (29) encourage shared decision making, including advocating for patients being informed to make decisions:

1.5.20 When discussing decisions about investigations and treatment, do so in a style and manner that enables the patient to express their personal needs and preferences.

1.5.21 Give the patient the opportunity to discuss their diagnosis, prognosis and treatment options.

1.5.22 When offering any investigations or treatments:

- *Explain the medical aims of the proposed care to the patient*
- *Openly discuss and provide information about the risks, benefits and consequences of the investigation or treatment options (taking into account factors such as coexisting conditions and the patient's preferences)*
- *Clarify what the patient hopes the treatment will achieve and discuss any misconceptions with them*
- *Set aside adequate time to allow any questions to be answered, and ask the patient if they would like a further consultation.*

62% of patients wanted to be fully informed about their illness and actively involved in treatment decision-making (23).

After ‘diagnosis’ and ‘soon after diagnosis’, the most popular choice to the BCUK 2019 survey question on when people needed the most information to support them was ‘during treatment’ (20%).

As with general questions on information, the volume of questions relating to patient information specifically regarding treatment in the UK Cancer Patient Experience Surveys are testament to its perceived importance. There are areas in CPES where people with haematological malignancies seem to be relatively well informed in relation to other cancers:

- Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand? - Yes, completely
- Beforehand, did you have all of the information you needed about your chemotherapy treatment? - Yes, completely

- Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand? - Yes, completely

However, again, these are outweighed by areas which are underperforming.

Evidence of unmet needs

18% of respondents to the BCUK 2019 patient survey said that, during treatment (including Watch and Wait), they were not given enough information. This ranged from 9% in high-grade non-Hodgkin lymphoma, to 25% in chronic leukaemias and 29% in “other” leukaemias.

Haematology respondents to England CPES 2019 scored significantly lower than the “all cancers” average, and lower than the “big four” when asked if their treatment options were explained to them before treatment started. Haematology respondents to the last Northern Ireland CPES survey were also lower than the average and “big four”.

Before your cancer treatment started, were your treatment options explained to you?
- Positive score (Yes, completely)



Scores were less positive from CML and multiple myeloma respondents.

England 2019 CPES Q14. Before your cancer treatment started, were your treatment options explained to you? - Positive score (Yes, completely)



Based on 9,259 responses

In the England CPES 2019 patients were asked if beforehand, they had all of the information they needed about their radiotherapy treatment. Haematological respondents were significantly less positive than the “all cancer” average, 84% compared to 86%.

Whether they occur temporarily during intensive treatment, after treatment has finished, or are ongoing due to treatment for a chronic disease, side effects of blood cancer treatment are an important issue.

In the results from England 2019 CPES blood cancer respondents were significantly less likely to say they definitely had possible side effects explained to them in a way they could understand.

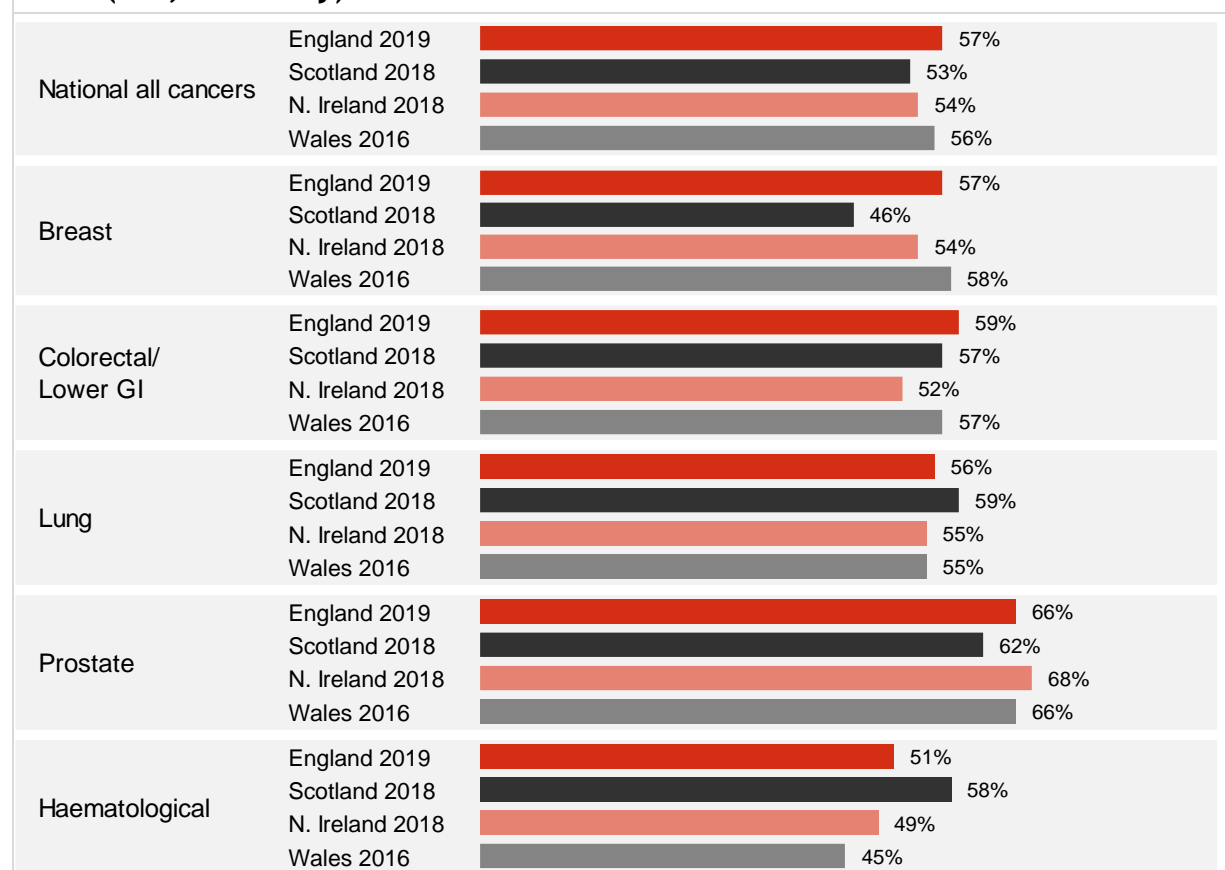
England CPES 2019 Q14. Were the possible side effects of treatment(s) explained in a way you could understand? - Positive score (Yes, definitely)



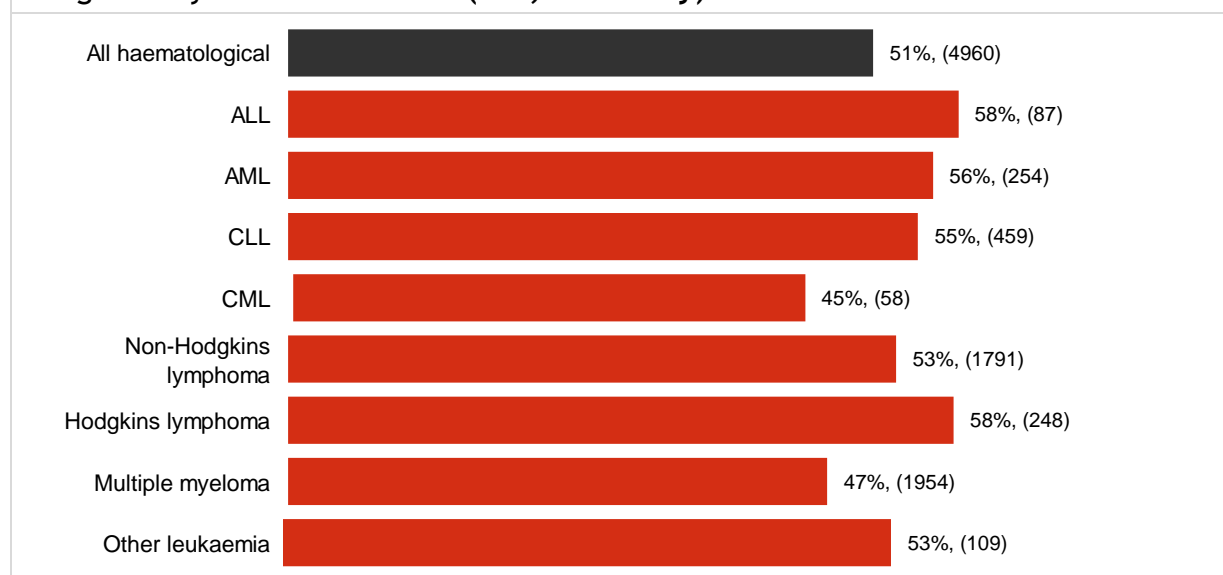
Based on 64,012 responses

Haematological respondents from the most recent iterations of the England, Northern Ireland and Wales CPES surveys were significantly less positive when asked if, before treatment started, that they were also told about any side effects of the treatment that could affect them in the future rather than straight away. In addition, the scores themselves are not high, indicating further improvement is possible in this area.

Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away? - **Positive score (Yes, definitely)**



England CPES 2019 Q17. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away? - **Positive score (Yes, definitely)**



Based on 9,725 responses

In England 2019 CPES, respondents were significantly less positive when asked if they were offered practical advice and support in dealing with the side effects of their treatment.

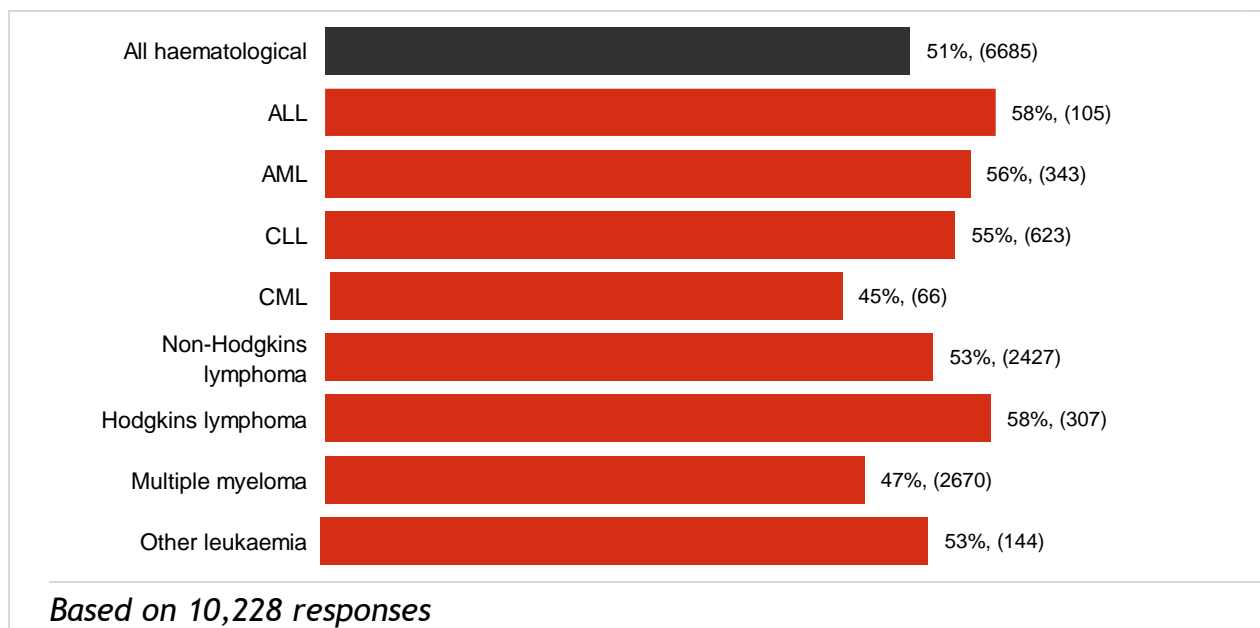
England CPES 2019 Q16. Were you offered practical advice and support in dealing with the side effects of your treatment(s)? - **Positive score (Yes, definitely)**



Based on 63,834 responses

Scores were even lower in multiple myeloma and CML.

England CPES 2019 Q16. Were you offered practical advice and support in dealing with the side effects of your treatment(s)? - **Positive score (Yes, definitely)**



3.3.3 Watch and wait

In the BCUK 2019 patient survey, people on Watch and Wait were more likely to say they needed information:

- soon after diagnosis (41% compared to 28%)
- around appointments / check-ups (11% compared to 9%)
- in the first year after diagnosis (13% compared to 4%) than other respondents to the survey

Furthermore, Watch and Wait was the only point asked about where people said information about the emotional impact of blood cancer was more important (60%) than practical things you can do to help yourself (55%).

Evidence of unmet needs

Of leukaemia respondents to the LC 2017 survey who were placed on Watch and Wait

- 60% said they fully understood the reasons why this was the case. 33% said they mostly understood the reasons and 7% did not understand the reasons.²
- 37% said that, when they were told they had been put on Watch and Wait, they were not given written information about it.³
- 12% said that hospital staff did not give them information for people with blood cancer, but they would have liked this. (This is compared to 8% of non-Watch and Wait respondents.)

Fewer Watch and Wait respondents were given both written and verbal information than their non-Watch and Wait counterparts - 63% compared to 71%.

² Calculation excludes those who said they did not need it.

³ Calculation excludes those who said they did not need it.

3.3.4 Beyond treatment: Evidence of unmet needs

23% of respondents to the BCUK 2019 patient survey said that, in remission, they were not given enough information.

13% of leukaemia respondents to the LC 2016 patient survey said that the results of their tests or monitoring were only partially explained in a way they could understand. 38% said they were not given a copy of their test results (from being tested or monitored) to take away with them, but they would have liked this. 9% said they were not told or informed of their test results.

3.3.5 Survivorship: Evidence of unmet needs

23% of respondents to the BCUK 2019 patient survey said that, if they'd been living with blood cancer for a year or more, they do not feel they have enough information.

3.3.6 Information relating to COVID-19

66% of respondents to the BCUK COVID-19 survey reported that they had received a letter advising them to shield - 28% had not.

3.3.7 Information for social support network

NICE Haematological cancers: improving outcomes guidance(6) states:

The MDT should: ensure that adequate information, advice and support is provided for patients and their carers throughout the course of the illness.

UK results of the LyC 2020 survey support that caregivers report playing a large role in gathering information for the patient - 42% seek information alone and 43% seek information with the patient. Furthermore, results show that 53% of caregivers report that a doctor would be their first place to go for information, should they need it.

This is an area that may benefit from further exploration in local surveys, but there is one question in the England 2019 CPES which asks about information for social support network: *Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?* 62% of blood cancer respondents replied positively that this definitely happened, and this score is better than the “all cancer” average, breast, lung and prostate scores.

3.3.8 Psychosocial - emotional / practical resource

Although there is crossover here with other chapters, where signposting and resources are a resolution to specific areas of unmet need, here will briefly address the informational side.

14% of respondents to the BCUK patient survey said that written / multimedia information about the possible emotional impact and coping were the most useful forms of support, more than charity support line (11%), online and face-to-face support groups (10% and 8% respectively).

Evidence of unmet needs

More than a third of respondents to the BCUK 2019 patient survey (34%) said they were not offered any information at diagnosis (written, verbal or otherwise) about the possible impact on their mental health and emotional wellbeing.

23% of leukaemia respondents to the LC 2016 patient survey said that hospital staff did not give them information about support or self-help groups for people with blood cancer, but they would have liked this. When people received this information, 13% only received it verbally. 31% said they understood some of it and a further 3% said they did not understand most of it.

As described in the Psychological Impact chapter; within the England 2019 CPES, when asked if hospital staff gave information about support or self-help groups for people with cancer, the haematological score was significantly lower than the all-cancer average, as well as below the “big four”.

England 2019 CPES Q22. Did hospital staff give you information about support or self-help groups for people with cancer? - Positive score



28% of UK respondents to the ALAN 2019 survey said their leukaemia healthcare team has never directed them to or provided them with information about emotional support for managing their disease and treatment, but they would have liked this. 23% of respondents said they were not directed to/provided with enough information on emotional support by their acute leukaemia healthcare team.

3.3.9 Information regarding financial help and benefits

This topic is covered in more detail in Chapter 5.

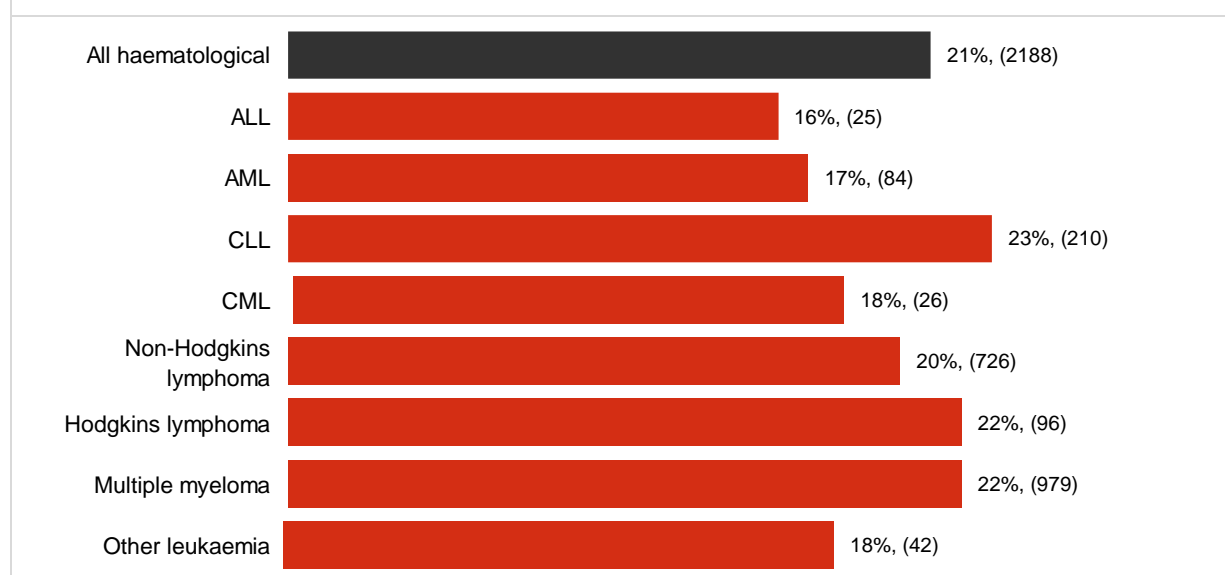
Evidence of unmet needs

There is evidence of unmet needs for the provision of information relating to financial help and benefits.

Within the ALAN 2019 survey, 28% of respondents who felt that information about how to get financial help or benefits was necessary did not receive it, but would have like to have done.

Overall, 1 in 5 blood cancer patients were not given information about how to get financial help or benefits, but would have liked to have received it. CLL, Hodgkin’s lymphoma and multiple myeloma were least well served in this respect.

England CPES 2019 Q24. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to? - **No, but I would have liked information**



Based on 5,650 responses

4. Healthcare Journey Needs

There is a level of care that all patients should be able to expect, much of which is outlined in national guidelines, however, in reality experiences vary. In order to establish unmet needs of blood cancer patients along the treatment pathway, we have compared the expectations outlined in NICE guidance with actual patient experience reported in CPES, BCA member surveys, the blood cancer dashboard and current literature.

This chapter will address specific needs that relate to key points in patients' healthcare journey.

4.1 Early diagnosis

Diagnosis of blood cancers was an area that had good representation within the scope of the literature review. As well as articles being published since 2015 and UK focused, the research looked at individual disease types, rather than grouping them all together under the haematology banner.

Earlier diagnosis is widely recognised as having a significant impact on cancer survival and quality of life. WHO defines early diagnosis as the early identification of cancer in patients who have symptoms of the disease: *The focus of cancer early diagnosis is people who have symptoms and signs consistent with cancer. The objective is to identify the disease at the earliest possible opportunity and link to diagnosis and treatment without delay. When done promptly, cancer may be detected at a potentially curable stage, improving survival and quality of life* (30).

The NHS England Long Term Plan (ambitions for cancer) (31) includes the aim that from 2028 three in four cancers will be diagnosed at an early stage. Similar publications in Scotland, Wales and Northern Ireland do not currently have equivalent specific aims, however all of them refer to the importance of early detection, referral and diagnosis.

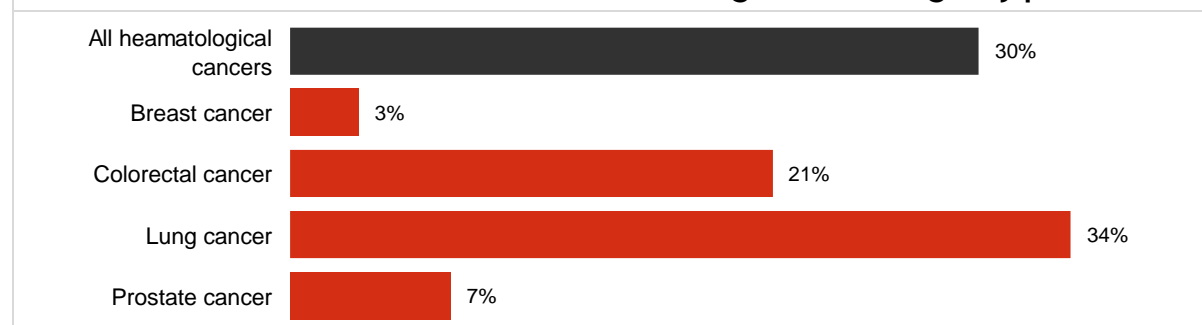
As there are no national screening programmes for haematological cancers, diagnosis has to rely on people recognising something is wrong and visiting a healthcare professional, and then the healthcare professional identifying an issue and taking further action.

Evidence of unmet needs

In England, the National Cancer Registration and Analysis Service (NCRAS) "Route to diagnosis" data can be used to analyse patients' journeys to their cancer diagnosis. Studies have shown that the emergency presentation route is often associated with a late or prolonged diagnosis and poorer outcomes in haematological cancers (32-35).

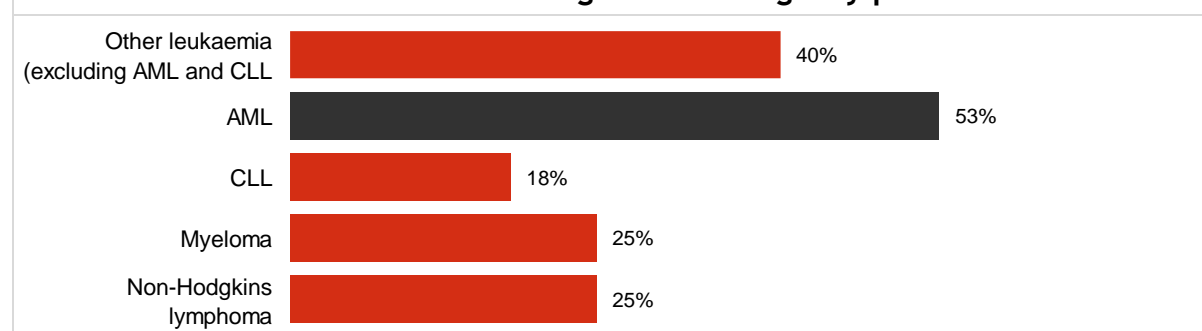
The blood cancer dashboard 2016 data illustrates that when compared to the “big four”, haematological cancers are second only to lung cancer for emergency admissions.

Blood cancer dashboard. 2017-2019 route to diagnosis - Emergency presentation



Further breakdown of route to diagnosis within the haematological grouping illustrates the difference present across the individual types. AML is the blood cancer that is more likely to present through an emergency admission, followed by other leukaemias (excluding CLL).

Blood cancer dashboard. Route to diagnosis - Emergency presentation



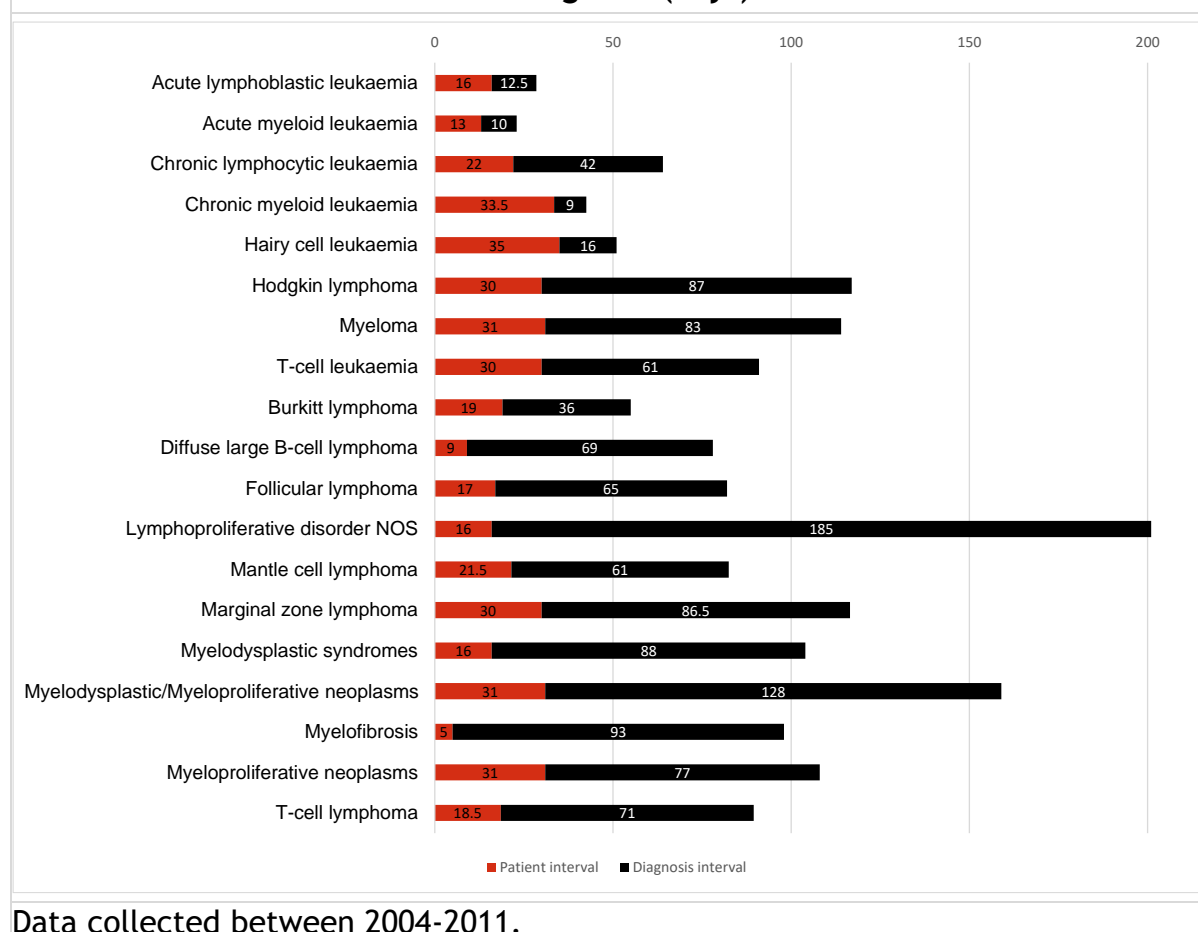
If we are to use emergency presentation as a rudimentary indicator of early diagnosis it would indicate that there is an unmet need for earlier diagnosis in blood cancers.

4.2 Specific factors that impact early diagnosis

The chart below illustrates the time between a patient noticing symptoms and their diagnosis⁴. The patient interval indicates the time between symptom onset to seeking help, and the diagnostic interval indicates the time between help seeking to diagnosis.

⁴ Blood cancer dashboard - accessed May 2021

Blood cancer dashboard. Time to diagnosis (days)



Data collected between 2004-2011.

The patient interval is shorter than the diagnostic interval across the majority of conditions. There are other noticeable differences across the blood cancer types, for example, acute leukaemias have the shortest overall diagnosis time, while lymphomas and myeloma are more prolonged. We found a number of studies that specifically investigated the diagnostic pathway for lymphomas and myeloma, and which illustrated the difficulties of how symptoms are interpreted and managed by both patients and GPs for these disease types (36-38).

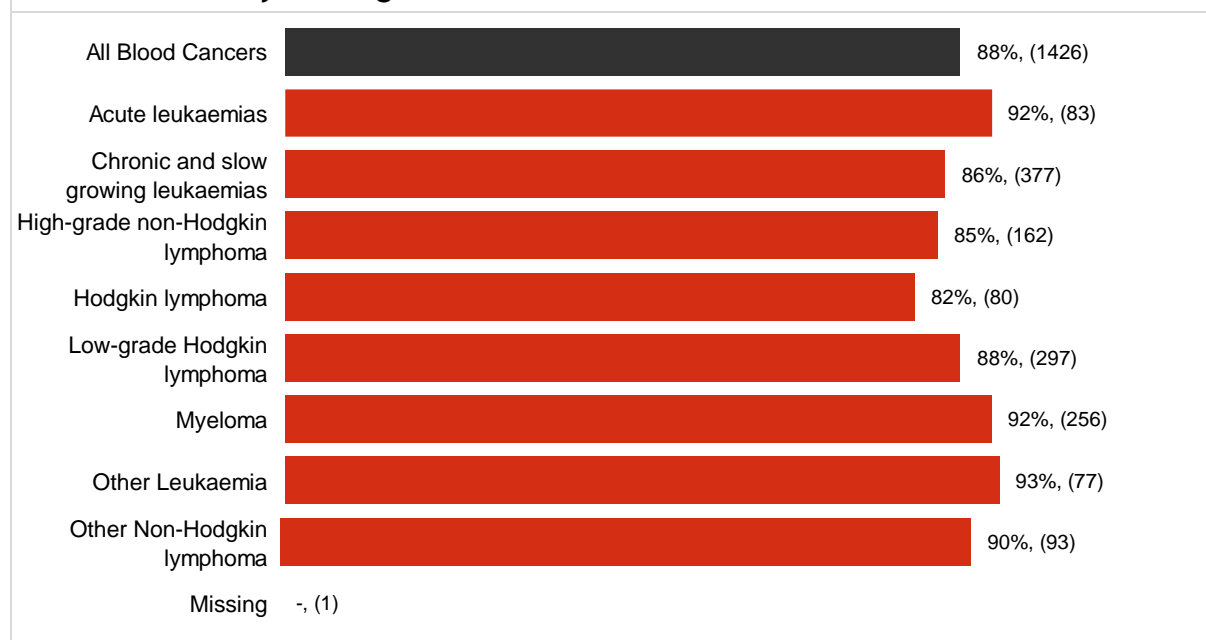
4.2.1 Public awareness of blood cancer symptoms

Unfortunately, the signs and symptoms of blood cancers can easily be associated with other health problems, as they are often vague and non-specific. This leads to people not recognising something might be wrong and delaying visiting their GP. This has been well documented in current literature (32, 33, 36, 37).

Evidence of unmet needs

88% of respondents to the BCUK 2019 survey said that they didn't know the signs and symptoms of their blood cancer/condition before diagnosis

BCUK 2019 Q13. Did you know the signs and symptoms of blood cancer or your condition before your diagnosis?- No



Based on 1634 responses

Public awareness and education campaigns are referenced as strategies within all current UK cancer plans. In England the National Awareness and Early Diagnosis Initiative (NAEDI) was announced in the Cancer Reform Strategy. This aim of this initiative is: *to co-ordinate a programme of activity to support local interventions to raise public awareness of the signs and symptoms of early cancer and encourage people to seek help sooner.*

However so far, the presence of blood cancers in these campaigns has been limited.

Past Be Clear on Cancer campaigns have included:

- Abdominal Symptoms Campaign
- 'Blood in pee' Campaign
- Bowel Cancer Campaign
- Bowel Screening Campaign (England)
- Breast Cancer in Women over 70 Campaign
- Know 4 Sure Campaign
- Lung Cancer Campaign
- Lung Cancer Awareness Wales Campaign
- Oesophago-gastric Cancers Campaign
- Ovarian Cancer Campaign
- Respiratory Symptoms Awareness Campaign
- Skin Cancer Campaign

The only inclusion haematological cancers can be said to have had in these campaigns is within Know 4 Sure Campaign. Within this campaign people were given four “key signs” to look out for:

1. Unexplained blood that doesn't come from an obvious injury
2. An unexplained lump
3. Unexplained weight loss, which feels significant to you
4. Any type of unexplained pain that doesn't go away

However, these symptoms are fully not representative of blood cancers and the way they can present.

It should be acknowledged that awareness campaigns for blood cancers is not straightforward. Some literature suggests that education campaigns on the main symptoms of blood cancers may not be as effective [as in other cancers] because of the variation present, they suggest a different approach of patients noting what is not “normal for them”. *For relatively rare conditions such as lymphoma, campaigns encouraging people to take note of changes in their body that persist and/or worsen, or diverge from what is ‘normal’ for them, maybe a more effective approach to encouraging help seeking (37).*

Regardless of these potential difficulties, there continues to be an unmet need for nationally instigated awareness campaigns, with this responsibility currently being shouldered by individual blood cancer charities.

4.2.2 Primary care awareness of blood cancer symptoms

As the “gatekeepers” to secondary care and diagnostic tests primary care professionals (most often General Practitioners, GPs) have a crucial role in the early detection of cancer. However, the complexities of recognising the symptoms of blood cancer also extend to GPs.

Current NICE referral guidelines make recommendations for tests or referral where the following symptoms are present.

Adults	Children
Pallor (pale skin)	Pallor (pale skin)
Persistent fatigue	Persistent fatigue
Unexplained fever	Unexplained fever
Unexplained persistent or recurrent infection	Unexplained persistent infection
Generalised lymphadenopathy (swollen lymph nodes)	Generalised lymphadenopathy (swollen lymph nodes)
Unexplained bruising	Persistent or unexplained bone pain
Unexplained bleeding	Unexplained bruising
Unexplained petechiae (tiny purple, red, or brown spots on the skin)	Unexplained bleeding
Hepatosplenomegaly (enlargement of the liver and spleen)	
Myeloma	
Adults	Children
Persistent bone pain, particularly back pain	
Unexplained fracture	
Non-Hodgkin's lymphoma	
Adults	Children
Unexplained lymphadenopathy (swollen lymph nodes)	Unexplained lymphadenopathy (swollen lymph nodes)
Unexplained splenomegaly (enlarged spleen)	Unexplained splenomegaly (enlarged spleen)
Associated symptom of fever	Associated symptom of fever
Associated symptom of night sweats	Associated symptom of night sweats
Associated symptom of shortness of breath	Associated symptom of shortness of breath
Associated symptom of pruritus (itchy skin)	Associated symptom of pruritus (itchy skin)
Associated symptom of weight loss	Associated symptom of weight loss
Hodgkin's lymphoma	
Adults	Children
Unexplained lymphadenopathy (swollen lymph nodes)	Unexplained lymphadenopathy (swollen lymph nodes)
Associated symptom of fever	Associated symptom of fever
Associated symptom of night sweats	Associated symptom of night sweats
Associated symptom of shortness of breath	Associated symptom of shortness of breath
Associated symptom of pruritus (itchy skin)	Associated symptom of pruritus (itchy skin)
Associated symptom of weight loss	Associated symptom of weight loss
Associated symptom of alcohol-induced lymph node pain	

However, this list is not exhaustive, and there are studies that have identified other potential symptoms (38).

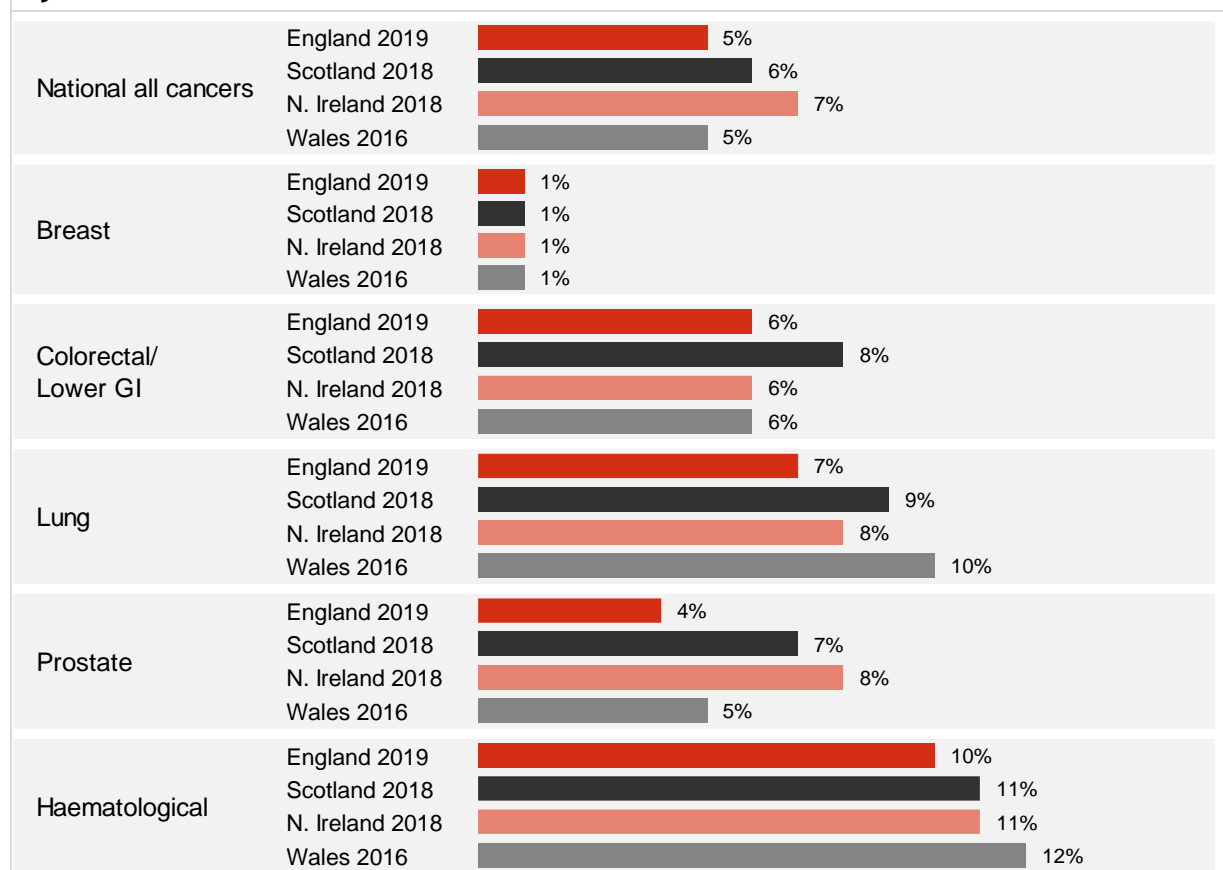
As previously stated, many of these symptoms can be associated with other conditions or thought to be self-limiting. GP's are often encouraged to consider "clusters" of symptoms, but this relies on patients reporting multiple potential symptoms, some of which they (the patient) may not consider to be connected or serious.

Evidence of unmet needs

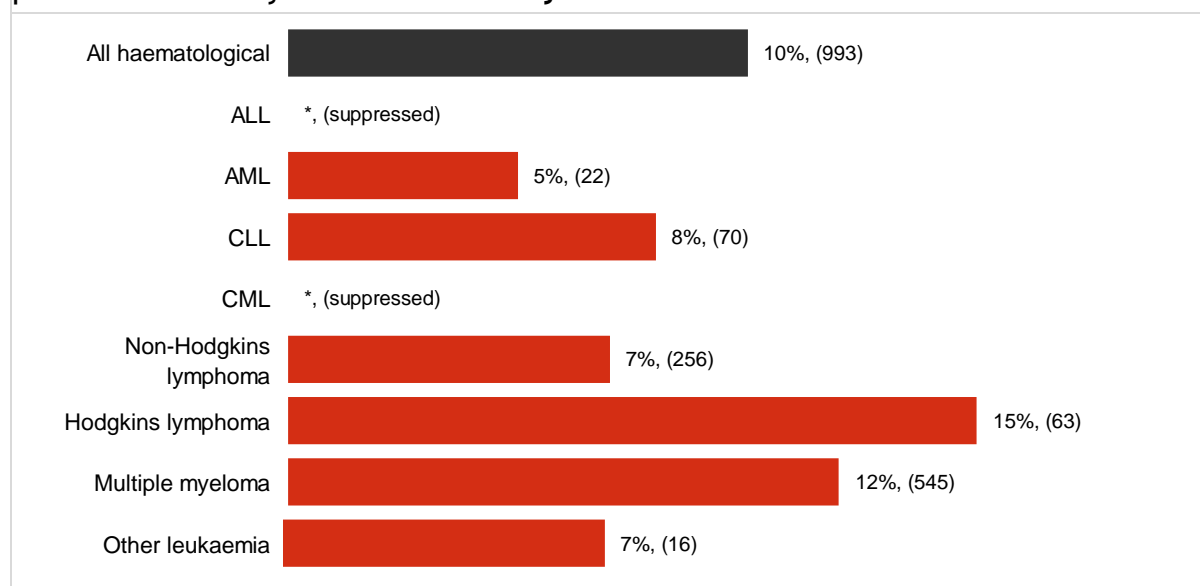
As illustrated earlier in the report, data across all the most recent CPES surveys indicate that as a whole, patients with haematological cancer are more likely to need to visit their GP more than 5 times than any of the "big four".

Further breakdown of the haematology group by blood cancer types (England CPES 2019) illustrates further disparity, with myeloma and Hodgkin's lymphoma patients more likely to report more than 5 visits.

Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problems caused by cancer? - I saw my GP 5 or more times



England CPES 2019 Q01. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer? - I saw my GP 5 or more times



Based on 10,304 responses

4.3 Clinical Nurse Specialists

A Clinical Nurse Specialist (CNS) is an invaluable part of a cancer patient’s healthcare team. They provide patients with information, help and support across practical and emotional needs, contribute to continuity of care and act as an advocate for the patient with other clinical staff. Results from England CPES surveys have demonstrated that that cancer patients who have access to a CNS generally report better experiences and understanding of the disease. *CPES tells us that the support of a Clinical Nurse Specialist is the most important contributing factor to people’s positive experience of care. They play a crucial role in providing information, enabling communication and in coordinating care (39).*

Similar results have been found in other UK iterations of CPES:

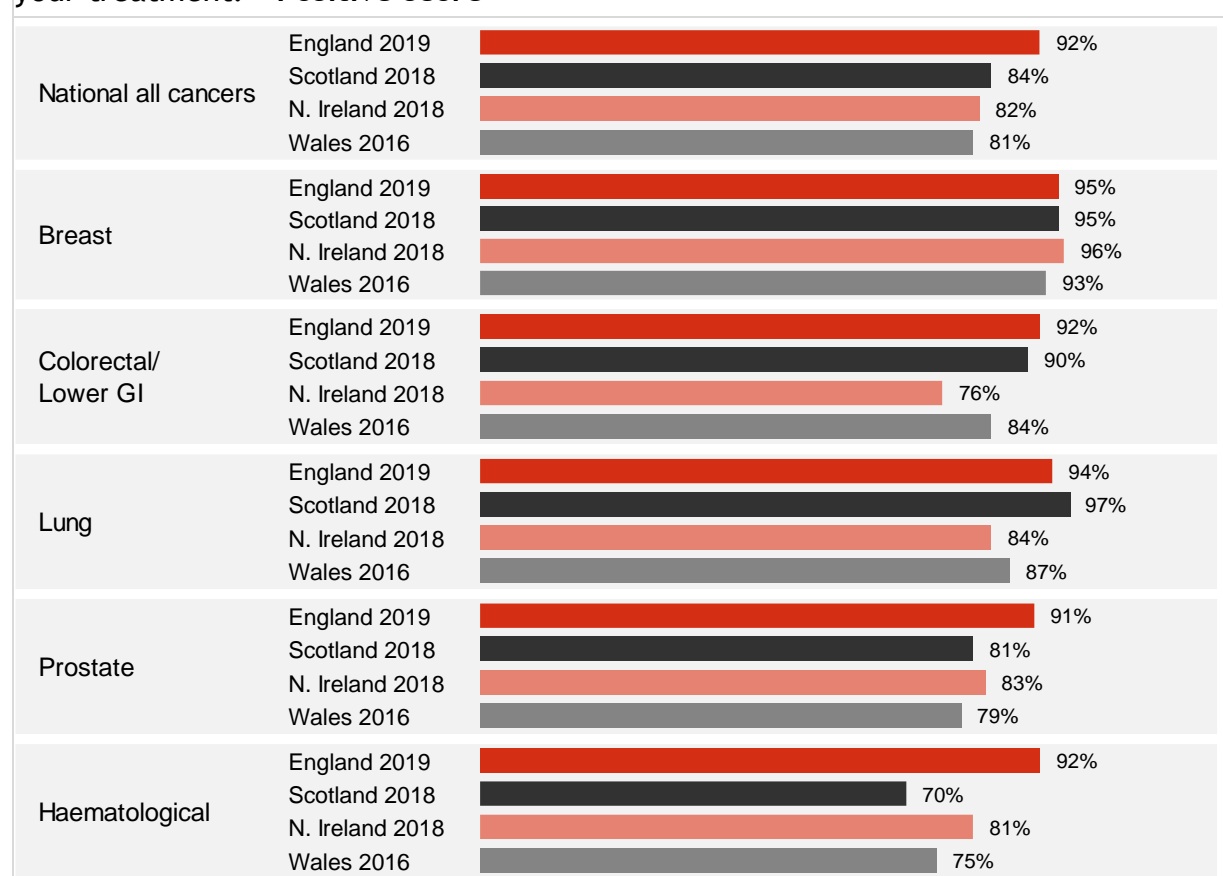
- Wales 2016 - Patients with access to a CNS reported having a significantly better experience for 73 out of 74 questions
- Northern Ireland 2018 - Patients with access to a CNS reported having a significantly better experience for 47 out of 48 questions

Nice Guidance Improving Outcomes in Haematological Cancers (6) recommends that: *From the time of diagnosis, each patient should have access to a specific clinical nurse specialist who can offer psychosocial support and continuity of care. Each patient and his/her carer should be given a telephone number so that they can contact this nurse when they feel they need information, help or support.* The NHS England Long Term Plan (31) states that: *All patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.*

Evidence of unmet needs

Results of the most recent iterations of CPES across the UK indicate that overall blood cancer patients in England were more likely to be given the name of a CNS. Scores for haematological patients were much lower in Scotland, Northern Ireland and Wales compared to the England score. In Scotland and Wales, the haematological scores were significantly below the National “all cancers” score.

Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? - **Positive score**



It is interesting to note the improvement that has been made in the haematological scores for CNS provision since 2015 in England. The 2015 score was significantly below the National “all cancers” average in 2015 but has steadily improved, in 2018 it was significantly better than the National score. Hopefully this illustrates how improvements can be achieved within other countries.

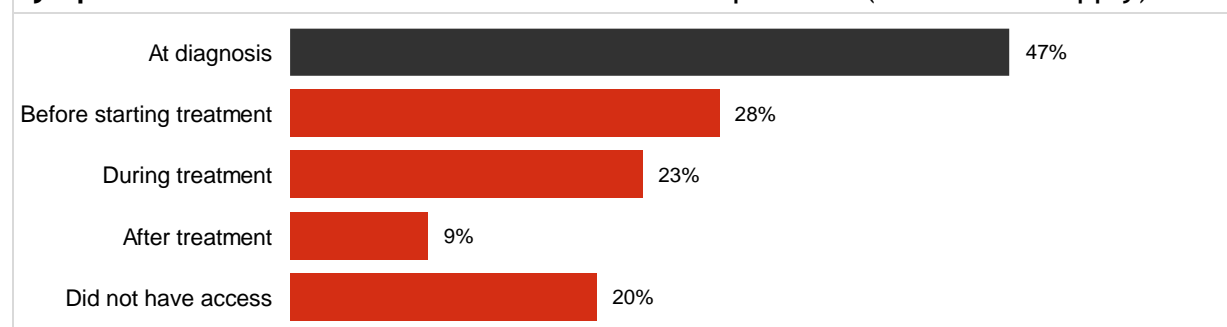
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? - **Positive score**



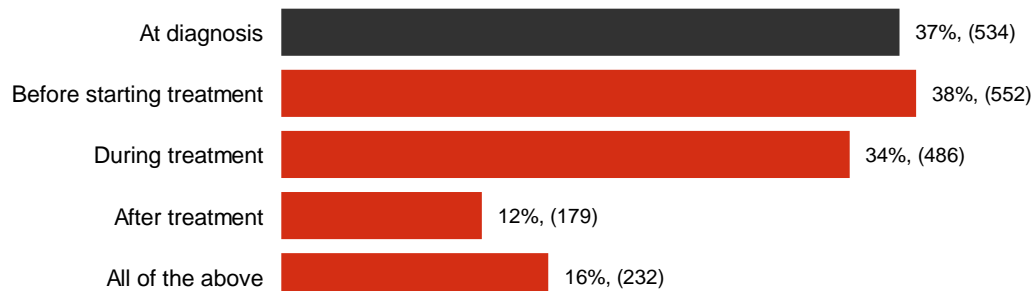
There is also evidence from the surveys run by BCA members and similar organisations that indicate access to a CNS is not always provided at diagnosis.

UK respondents to the LyC 2020 survey showed that less than half (47%) were given access to a CNS at diagnosis. Within the LC 2017 survey, just over half (53%) of leukaemia respondents said they were given access at diagnosis.

Lymphoma Coalition. Access to a Clinical Nurse Specialist (Tick all that apply)



LC 2017 Q51. If you were given access to a Clinical Nurse Specialist, when was this?
(Tick all that apply)



Based on 1439 responses

4.4 Specific factors that impact CNS provision and contribute to unmet needs

4.4.1 Blood cancer type

Results by blood cancer type from the England CPES 2019 indicate that there is some inequality for CNS provision. Non-acute leukaemias scored worse than all other types of blood cancer.

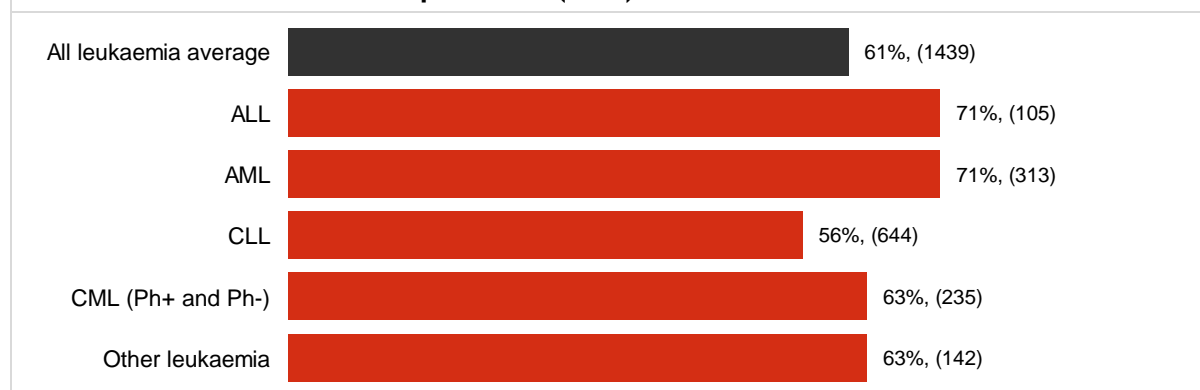
England CPES 2019 Q19. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? - **Positive score**



Based on 10,557 responses

This finding is supported by the results from the LC 2017 survey, where patients with an acute leukaemia were also more likely to say that they had been given access to a CNS.

LC 2017 Q49. Were you offered additional support in any of the following areas - Access to a Clinical Nurse Specialist (CNS)



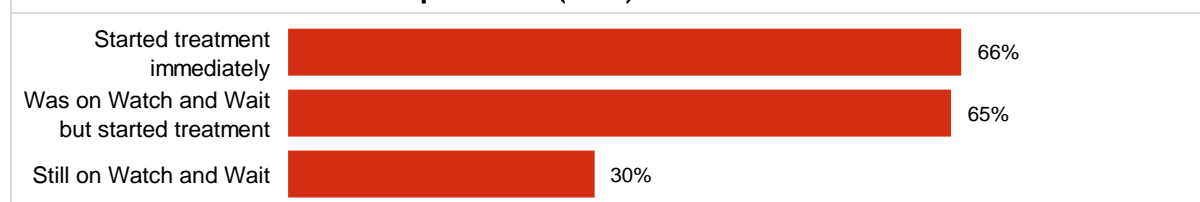
Based on 2340 responses

4.4.2 Watch and Wait

As previously stated, blood cancer patients on Watch and Wait are not fully represented in CPES surveys due to the sampling criteria.

Analysis of data collected by LC in 2017 illustrated that leukaemia patients currently on Watch and Wait were less likely to say they were offered access to a CNS than patients who started treatment straight away, or who were previously on Watch and Wait but had since started treatment.

LC 2017 Q49. Were you offered additional support in any of the following areas - Access to a Clinical Nurse Specialist (CNS)



68% of Watch and Wait patients surveyed by BCUK in 2019 said that they were given the name of a CNS to support them through their treatment or care pathway.

Blood Cancer UK Q78. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment or care pathway? - Positive score



4.5 Clinical trials

Improvements in the management of haematological cancers (as for solid tumours) require reliable evidence that interventions are effective and that they improve outcomes for patients. It is therefore important that health service commissioners should support the well-designed clinical trials within the National Cancer Research Network (NCRN) portfolio. There should be network-wide co-ordination of local participation in NCRN clinical trials in haematology through each cancer research network. Haemato-oncologists should regularly review the national portfolio of recognized studies and identify those they wish to support at local research network level. The possibility of entry into an appropriate trial should be discussed with every patient who fits the inclusion criteria. Such patients should be given accurate and accessible information to inform their decision about whether to participate in the trial. (6)

Clinical trials are important from a patient's perspective as they can provide access to new treatment options that are otherwise not available.

Evidence of unmet needs

In his foreword to the NICE Improving Clinical Outcomes in Haematological Cancers, Chairman of the National Cancer Guidance Steering group, Professor R A Haward comments that: *An admirable feature of British clinical haematology has been the widespread interest, and active participation of clinicians and hospitals, in clinical trials. Indeed, many national trials in these diseases have been extremely well supported by haematologists in all types and sizes of hospital, with high rates of trial entry (6).*

All UK iterations of CPES ask very similar questions about if patients have had a discussion about taking part in cancer research⁵. The scores for haematological

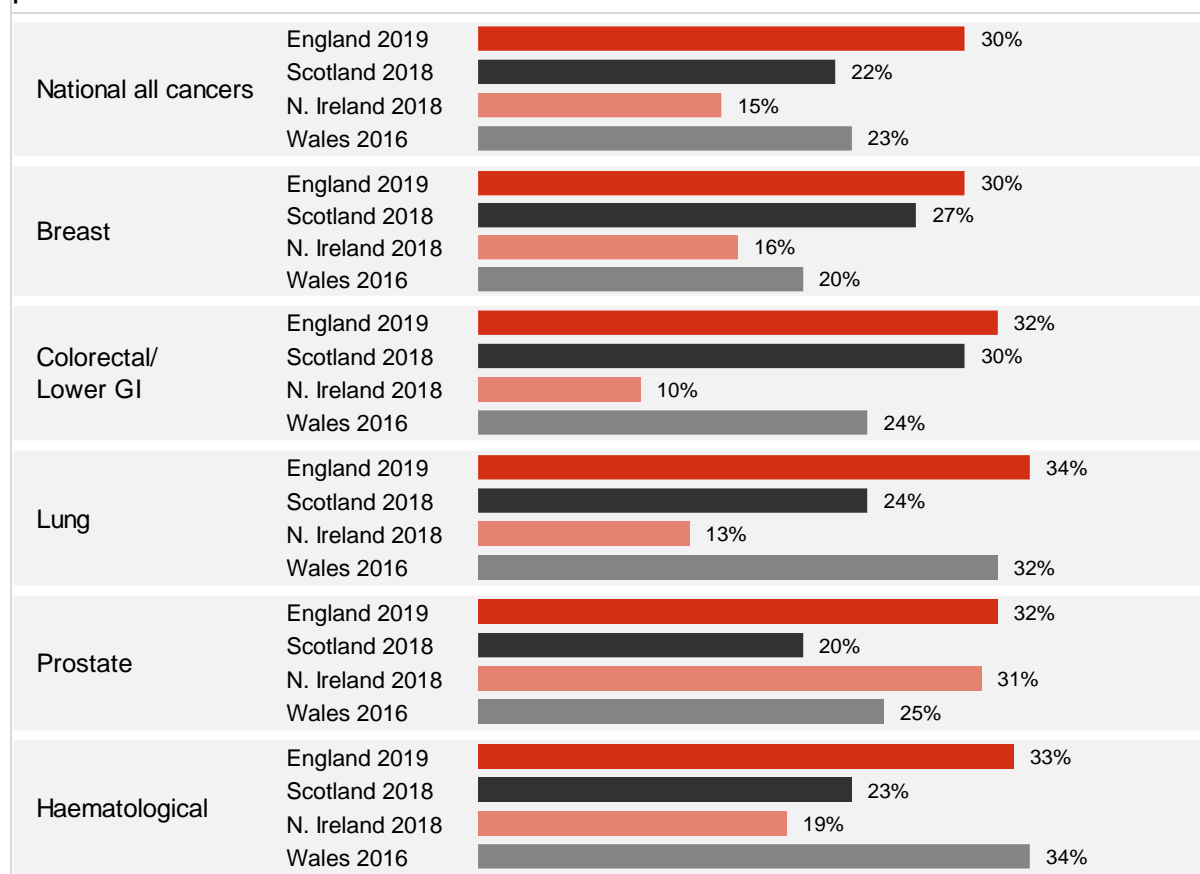
⁵ England 2019: Scotland 2018: Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?

Northern Ireland 2018: Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research for example clinical trials?

Wales 2016: Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?

patients were more positive in the England and Wales than their Scotland and Northern Ireland counterparts. Scores were mixed compared to the “big four” across all iterations, although as a whole the haematological groups performed well in comparison to the “all cancer” averages.

Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research? - **Positive score**

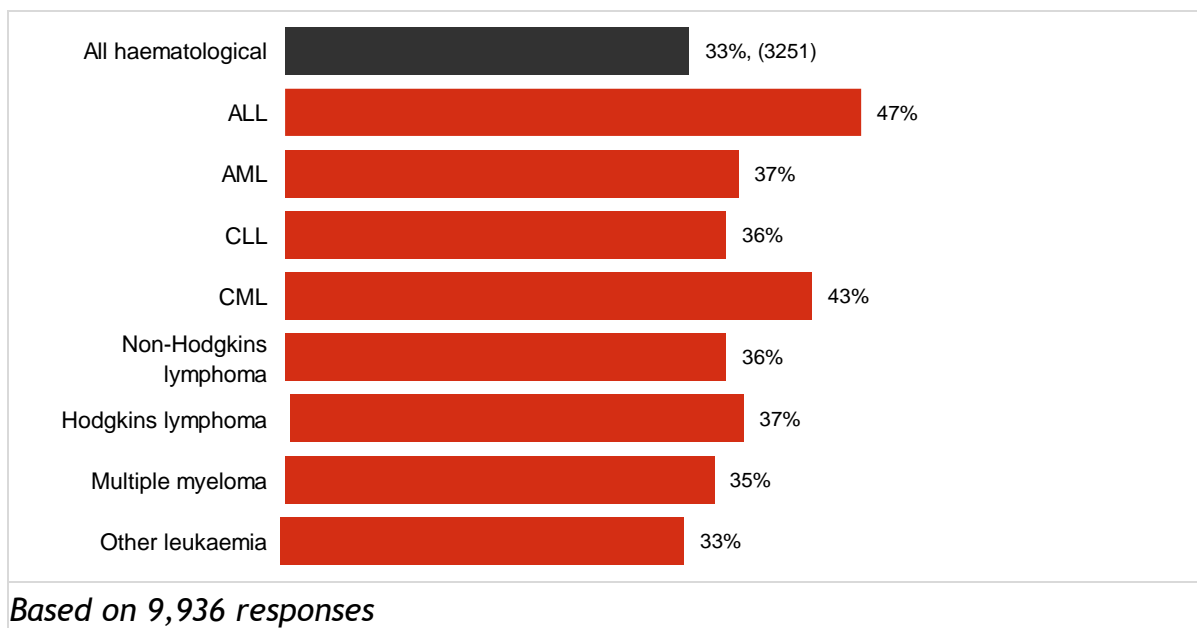


Despite this there is some evidence of inequality in access to clinical trials.

4.5.1 Blood cancer type

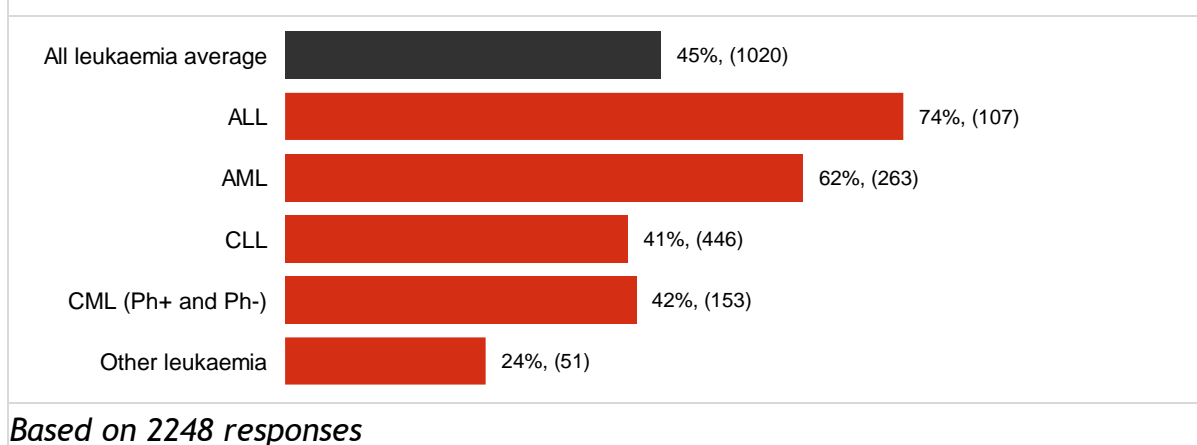
Breakdown by disease type shows better results within ALL and CML, while ‘other leukaemia’ and multiple myeloma have the lowest scores.

England CPES 2019 Q60 Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research? - **Positive score**



Results amongst respondents from the LC 2017 were more positive. While overall less than half (45%) of leukaemia respondents said that they were given the option of participating in a clinical trial, this varied greatly between types. 15% of HL, 18% of NHL and 50% of myeloma said that they were given the option.

LC 2017 Q29. Were you given the option of participating in a clinical trial - Positive score

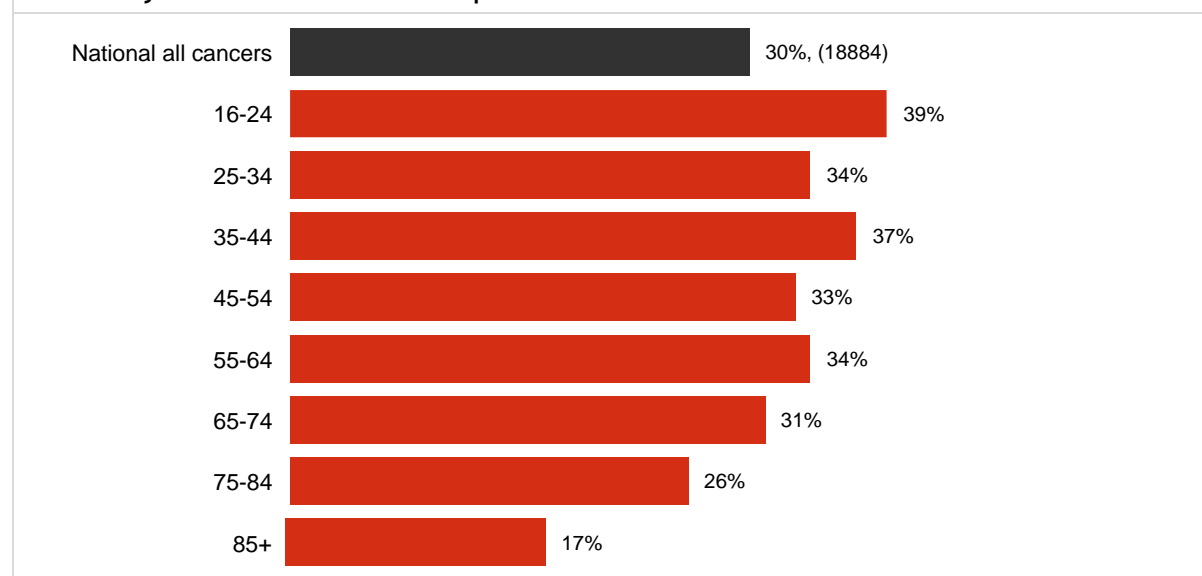


Results from the LyC 2020 UK data showed that only 9% of patients are currently, or have ever been, in a clinical trial for their lymphoma or CLL. 54% of patients who are having or had treatment say that they have not been presented with the opportunity to participate in a clinical trial. 54% of respondents felt that not being presented with an opportunity to participate in a clinical trial was the biggest barrier to being in one, with a further 10% stating that clinical trial availability is a barrier.

4.5.2 Age

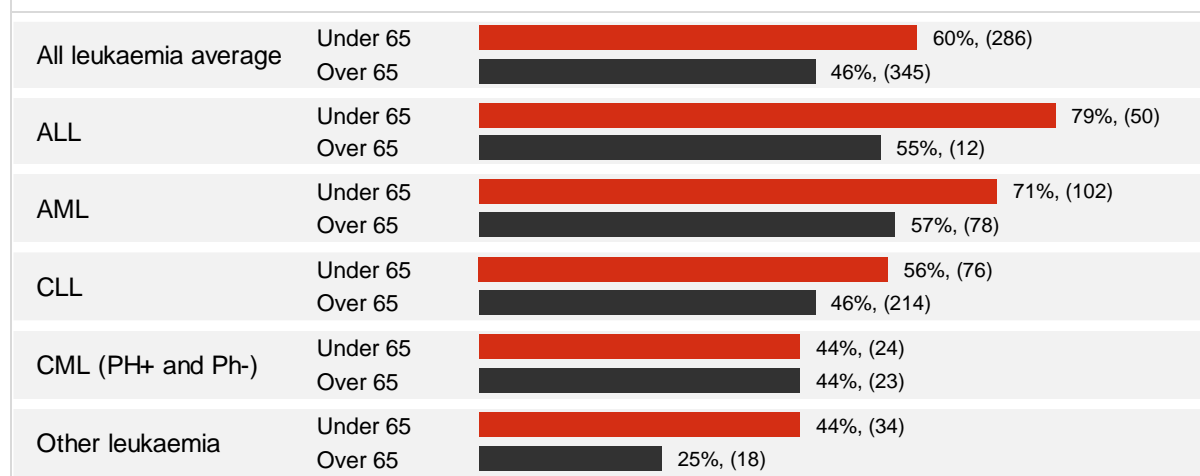
The NCIN report Older People and Cancer (40) acknowledged that evidence from the English CPES (2014) showed that people over 75 were less likely to have cancer research discussed with them (21%). 2019 data shows that 26% of 75-84 year olds and 17% of those over 85 have had discussions about cancer research, these remain lower than the other age groups.

England CPES 2019 Q60 Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research? - Positive score



Leukaemia Care reported on this issue using data from their 2016 survey (I wasn't born yesterday), illustrating that within their respondents, patients who were 65 and over were less likely to be given the option of participating in a clinical trial across all but one leukaemia type.

LC 2016 Q27. Were you given the option of participating in a clinical trial - Positive score



Based on 1230 responses

In 2017 the British Society of Haematology reported on a survey run by their Lymphoma Specialist Interest Group (SIG) on treatment patterns of Hodgkin's lymphoma in the elderly (41). Study organisers highlighted the importance of the results: *Older patients are excluded from both the determination of prognostic scores and the majority of clinical trials....Including older patients in more front line trials may improve upon the disproportionately poor outcome and identify a standard of care.*

4.5.3 Place of treatment

There was also one piece of literature that suggests patients who receive care at specialist clinics are more likely to be enrolled in clinical trials. McCulloch et al. (42) reported that between 2004 to 2015, 58.7% of patients with mantle cell lymphoma treated at a UK specialist clinic were enrolled on a least one clinical trial, compared 9% in the comparison population. Furthermore, clinical trials open at the specialist treatment clinic provided access to: *novel agents that were otherwise unavailable.* They also reported how Ibrutinib was first used in a clinical trial at the clinic in 2011 but only became available via the Cancer Drugs Fund in 2015.

4.6 Access to treatment

Treatment for blood cancers is often more complex than their solid tumour counterparts. In recent years more treatments have been developed, leading to improved outcomes for blood cancer patients. However, there are issues with blood cancer patients being able to access these new medicines and treatments.

BCA has reported on rapid access to treatment within blood cancer which covers the complexities and issues faced in this area (43). This research included a survey of patients and/or carers of people with blood cancer, which received over 700 responses.

The survey reported that more than four fifths of blood cancer patients believe the Government (88%) and the pharmaceutical industry (81%) should do more to ensure patients can access new treatments.

The report also identified 10 key issues that impact on access to treatment:

1. New blood cancer treatments are coming through and HTA agencies and companies need to prepare for their appraisal.
2. It is vital to involve patients from Research and Development and beyond and for their involvement to have an impact.
3. Modifiers - additional factors that are not easily incorporated into approach to the clinical and economic evidence used in Health Technology Assessment (HTA) - play a role in HTA but need revisiting.
4. The Cancer Drugs Fund (CDF) has enabled access for blood cancer patients but a change to an Innovative Medicines Fund is causing concern for future access.
5. Uncertainties are a common feature in the evidence base for blood cancer treatments at the time of appraisal and real-world evidence could help.
6. The CDF has enabled access for blood cancer patients and enables the generation of further evidence when there are uncertainties at the time of first appraisal. However, within the CDF the evidence that NICE needs to counter uncertainty at the time of the first NICE appraisal is not always being collected.
7. Non-submissions are rising in blood cancer. Key drivers include the challenge of combination pricing and the lack of multi-indication pricing.
8. There is more potential for outcome-based payment where companies are rewarded on the basis of the outcomes that their treatments generate.
9. Submissions to NICE have errors; submissions need to improve
10. Speedy access requires speedy collaboration.

Evidence of unmet needs

There is evidence that blood cancer patients already report issues getting the right treatment. Results from the report survey indicated that 8% of respondents found it difficult or very difficult to get the right treatment(s) for their condition.

Furthermore just under a quarter of respondents (23%) agreed/strongly agreed with the statement “I cannot/could not access a treatment that is available in countries outside of the UK”, and one in ten (11%) agreed/strongly agreed with the statement “I cannot/could not access a treatment that is available in another part of the UK”.

Looking forward, two thirds (67%) of blood cancer patients surveyed as part of the BCA report were concerned about accessing treatments that are in development in the future, with one in ten (11.5%) reporting extreme concern.

4.7 End of life care

End of life care is an important subject to address across all health conditions. NICE have published a detailed guideline that contains recommendations focused on care of dying adults in the last days of life (44). Reference to end of life care is also discussed in the NICE guidelines Improving supportive and palliative care for adults with cancer and Improving Clinical Outcomes in Haematological Cancers (6, 8). The former states the objective for care of dying patients *“that all patients have a dignified death, with family and other carers adequately supported during the process”*. End of life care is also encompassed within the Achieving World Class Outcomes (39): *“Improving peoples experience needs to be prioritized across the pathway, including at the end of life: Cancer patients at the end of their lives are often not experiencing the care that they would choose. We need to provide appropriate integrated services for palliative and end of life care”*

Evidence of unmet needs

The Haematological Malignancy Research Network have run several studies examining the preferred and actual place of death in haematological malignancies, the ones within the scope of the literature review were Howell et. al, 2015 (45) and Sheridan et. al (46). Both studies included AML, DLBCL and myeloma patients, although the more recent study had patients with 23 subtypes. Important findings in relation to unmet needs were:

- Only around a half of patients had a discussion about their preferred place of death, 44%/51%.
- Of those patients who had a discussion 63%/67% died in their preferred place.
- In both studies patients who did not have a discussion were more likely to die in hospital.

A patient’s preferred place of death may not always be possible, as it may be necessary to deliver end of life care elsewhere, due to the complexities around blood cancers, for example sudden deterioration. However, to meet expectations of patient involvement, there should be the opportunity for discussions on end of life care.

4.8 COVID-19

While it is possible to report on some of the impact that COVID-19 has had on the treatment journey of blood cancer patients, it is still very early to be able to identify unmet needs.

47% of respondents to the BCUK COVID-19 survey reported that their blood cancer appointments and treatment had been impacted in some manner by the pandemic. 45% of respondents with scheduled care had not been attending their appointments during the COVID-19 pandemic due to disruptions outside of their control e.g. due to appointment cancellations or postponement. 7% of those with scheduled care had not been attending their appointments out of choice, mainly due to concerns about attending hospital in a pandemic.

Changes to appointments were also reported within CLL patients surveyed by LC in 2020. 32% of respondents had an appointment delayed or moved, and 42% said that their appointment was conducted by phone or video. With regards to treatment, 14% of respondents reported that this had been disrupted or suspended as a result of isolating or hospital visit changes. 53% of patients had not been told when treatment will start again.

Over a quarter (27%) of respondents to the LUK 2021 survey had experienced an impact on their treatment due to COVID-19. Within these 10% had a test or scan delayed or rescheduled and 6% had treatment delayed or rescheduled.

5. Financial Needs

This section will encompass the financial impact of a blood cancer diagnosis in the UK and the needs that this incurs, including impact on employment, additional costs and effect on social support network.

While in other areas of need, to an extent it was possible to consider relevant literature from beyond the UK as relevant to the needs of UK patients, the nature of varying public health funding and country-specific financial support mechanisms make much of the literature from outside the UK on this subject less applicable or not at all applicable to people in the UK.

There has been literature written on the financial impact of cancer in the UK, but these were prior to 2015, (47) (48) and are focussed on the needs of people with cancer in general. There was a lack of haematological-focused articles about financial impact or needs.

Surveys from BCA members and global surveys have collected data on the impact of blood cancer on finances:

- 43% of leukaemia respondents to the LC 2017 survey said they had experienced a negative financial impact as a result of having cancer,
- 45% of UK respondents to the ALAN 2019 survey said that their acute leukaemia has had a negative effect on their finances.
- 97% of respondents to LUK 2021 survey reported a negative effect on their financial wellbeing in the short term (around diagnosis and treatment)
 - 55% small negative impact
 - 26% medium negative impact
 - 16% large negative impact
- 99% of respondents to LUK 2021 survey reported a negative effect on their financial wellbeing in the long term (after treatment was completed)
 - 65% small negative impact
 - 20% medium negative impact
 - 14% large negative impact

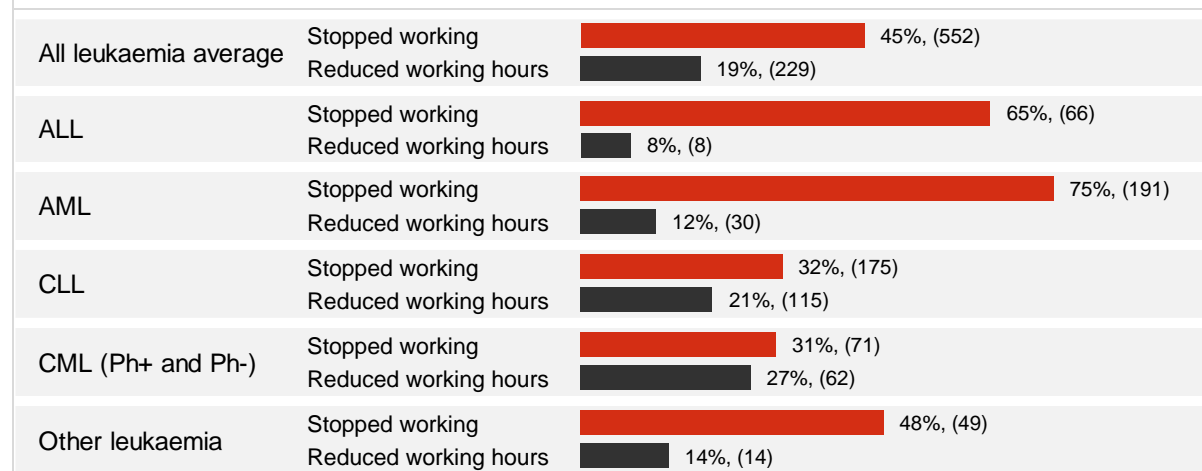
5.1 The impact of blood cancer on ability to work

Individuals' finances / financial needs and their ability to work are intrinsically linked, as the vast majority of adults will only receive money from their job or employment. Patients with blood cancer may have to take time off work, reduce their working hours or stop working completely due to hospital admission/appointments, disease symptoms or the side effects of treatment.

Of the UK respondents to LyC 2020 survey, 38% said they had been unable to work or had changed their working pattern because of the side effects of treatment.

When asked how their diagnosis has affected their ability to work or complete education, 45% of leukaemia respondents to the LC 2017 survey said they had to stop working, with 19% saying they had to reduce their working hours. Of those who said they reduced their working hours, 24% said it was permanent and 76% said it was temporary; and, of those who stopped working, 55% said it was permanent and 45% reported it was temporary. While those with acute leukaemia were more likely to have stopped working, it was those with a chronic leukaemia who were most likely to report a permanent impact on their ability to work.

LC 2017 Q33 How has your diagnosis affected your ability to work or complete education?



Based on 1334 responses

5.2 Additional costs incurred by blood cancer patients

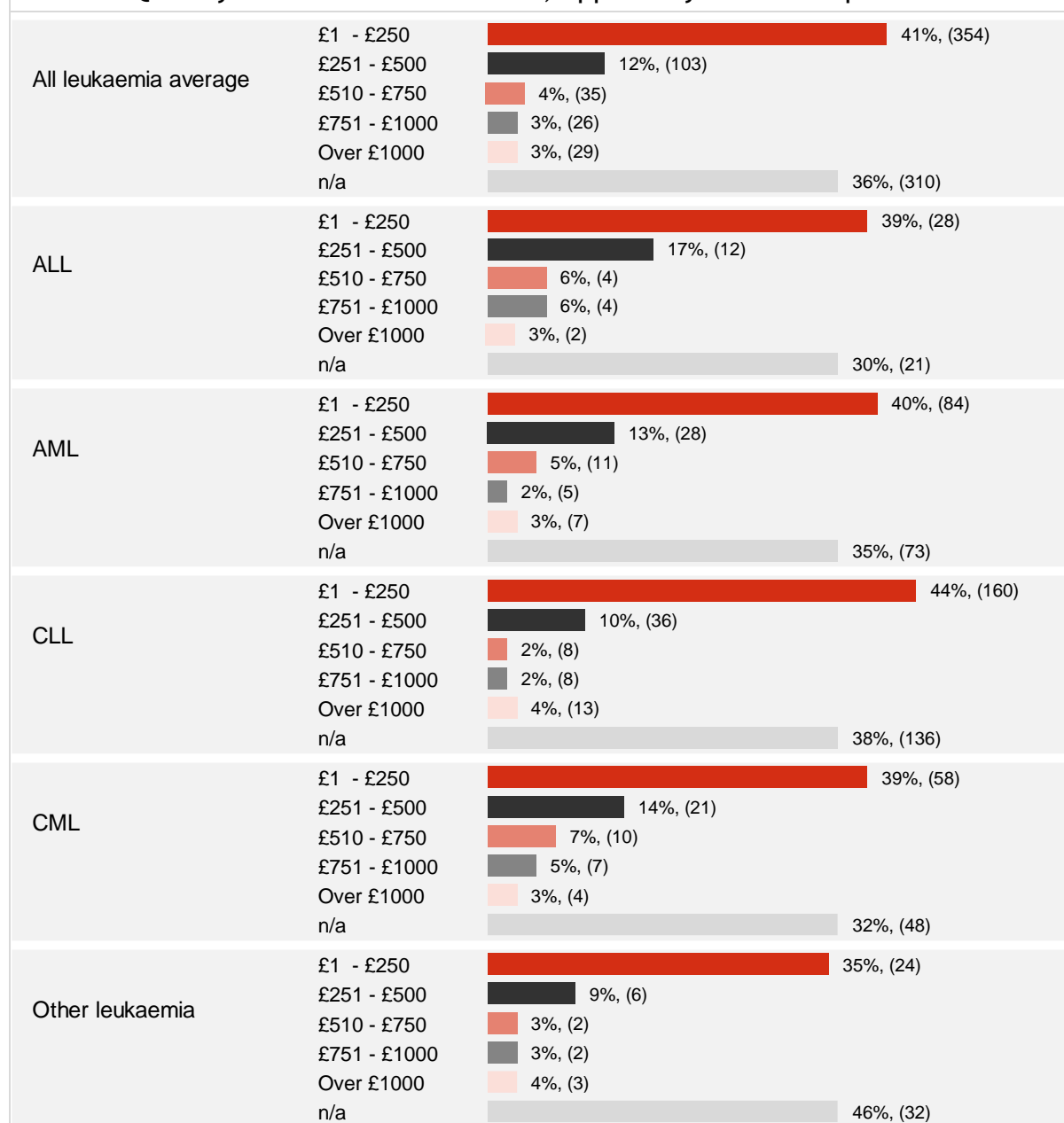
In addition to changes to their ability to work, blood cancer patients will often incur additional costs. These can be related to the associated costs of hospital visits (inpatient or outpatient) such as travel and parking, specialist clothing, equipment or home modifications, and changes in day to day living expenses.

In a 2013 study (47) researchers reported that lymphoma, leukaemia or myeloma had a median financial impact of £181 (and mean of £500) per month. This figure was higher than the big four:

- Breast - Median £120, Mean £427
- Lung - Median £118, Mean £376
- Colorectal - Median £105, Mean £326
- Prostate - Median £52, Mean £264

In the LC 2017 survey, out of the patients who reported a negative financial impact, 64% said that they have experienced an increase in their monthly costs. The majority (41%) reported an increase of between £1- £250 per month, 12% reported between £251 - £500, and 11% reported an increase of more than £500 per month.

LC 2017 Q36 If your costs have increased, approx. by how much per month?



Based on 857 responses

5.3 Financial impact on family, friends and carers

It is not always just the patient who will experience an impact on their finances; the people close to them may have to change their working patterns to help give care or even provide direct financial support to the patient.

Within the UK carers who responded to the LyC 2020 survey, a third reported that their working life was impacted by caring or supporting somebody with lymphoma/CLL.

They also reported experiencing the following issues to some extent (sometimes/often/always):

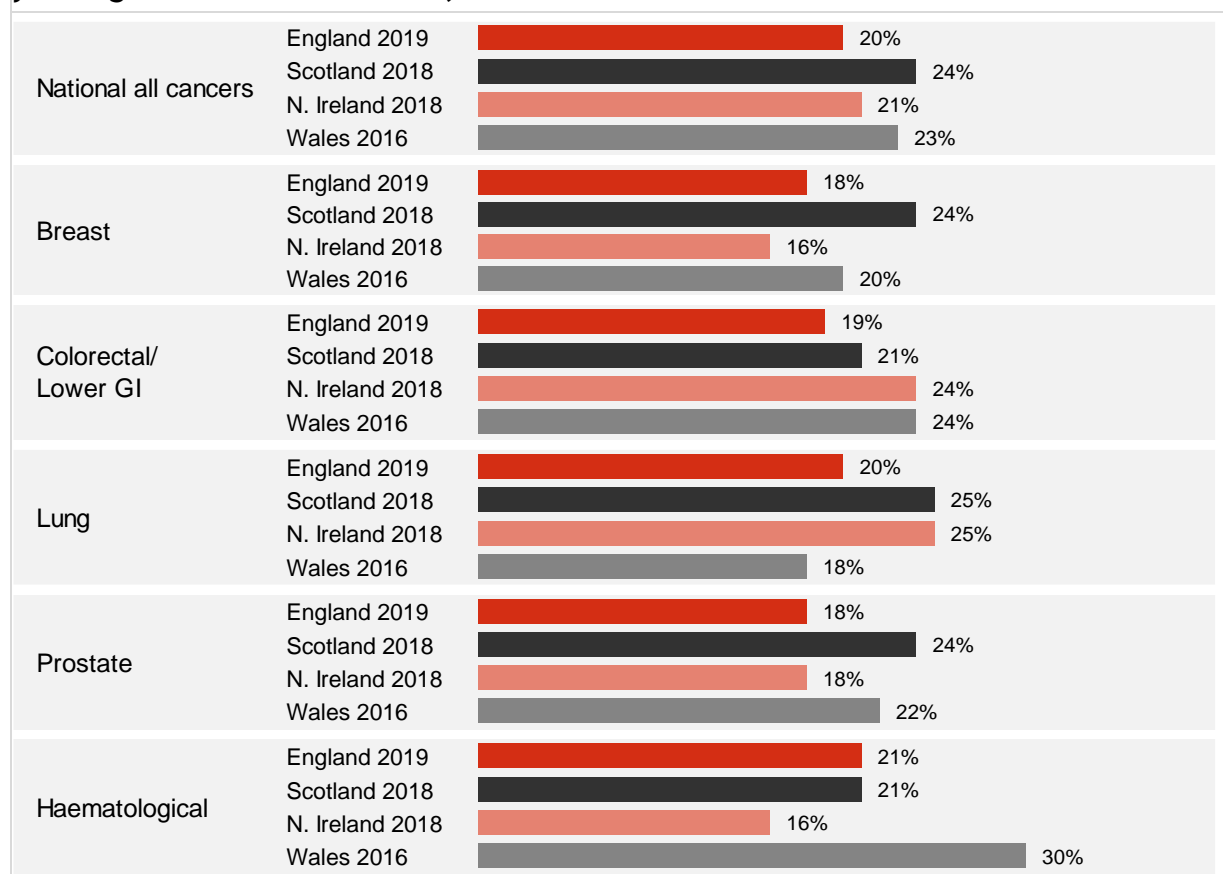
- Taking time off work - 45%
- Paying for a professional caregiver - 2%
- Paying for childcare - 12%
- Financial hardship due to reduced work - 20%

Within the UK respondents to the ALAN survey, 49% felt that their disease has had an impact on the finances of their family, friends or carer - 22% definitely and 27% to some extent.

Overall evidence of unmet needs

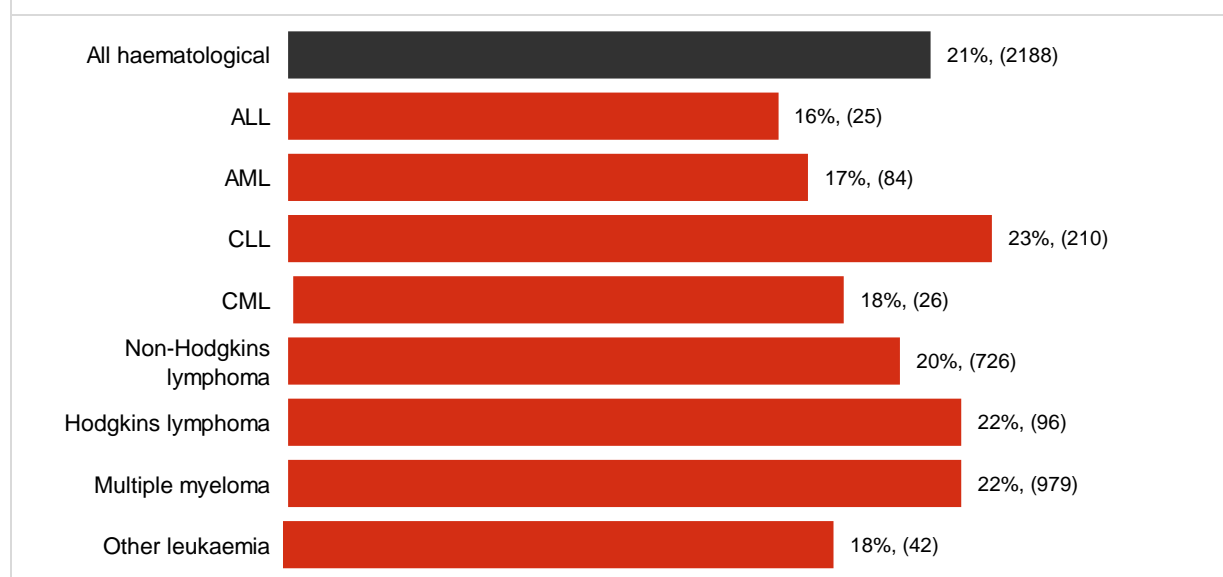
All of the most recent iterations of CPES ask a question about if hospital staff gave information about getting financial help and benefits. Looking at the results for those patients who said “No, but I would have liked information”, it is clear that there is disparity across countries and cancer types. The scores for haematology range from 16% in N. Ireland to 30% in Wales.

Did hospital staff give you information about how to get financial help or any benefits you might be entitled to? - No, but I would have liked information



Scores for the individual blood cancer types from England CPES 2019 indicate that patients with CLL, Hodgkins lymphoma and multiple myeloma are less likely to be given information about financial help and benefits.

England CPES 2019 Q24. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to? - No, but I would have liked information



Based on 5,650 responses

Acute leukaemia UK respondents to the ALAN 2019 survey echo the CPES results with a similar proportion saying that their healthcare team has never directed them or provided them with information about how to get financial help or any benefits they might be entitled to, but they would have liked this. Of those who were given information 16% said they were not given enough. 23% of respondents to the ALAN survey said that, as a result of their acute leukaemia, they have needed to rely on family, friends or carers to give them financial support - 7% completely and 16% to some extent.

An area that has been less investigated is the experiences of blood cancer patients attempting to access financial support and benefits, how easy or difficult the process was, if they were approved and if it helped.

5.4 Financial impact of COVID-19

In the UK, people with blood cancer are classed as “extremely vulnerable” to the coronavirus and were advised to shield during the pandemic. The impact of shielding led to changes in work circumstances for some patients, which in turn had an impact on their finances. The main change for many people was being put on furlough, while this scheme allowed the government to cover 80% of people’s wages, it was up to the employer if they covered the additional 20%.

Surveys run by BCUK and LC highlighted the following points around employment:
BCUK (people with blood cancer)

- 16% of working respondents were furloughed
- 13% received sick pay

LC (people living with CLL)

- 11% said their employment status changed
- 57% were initially furloughed
- 33% were furloughed in the most recent survey iteration
- 9% were unable to work due to shielding and unable to work from home
- 6% lost their job because of the pandemic
- 6% saw a reduction in work because they are self-employed

There was also an increase in cost for some shielding patients, associated with increased household utility bills and food costs. In the LC survey, respondents were asked what they thought were the main reasons for their increased costs:

- 37% increased food costs
- 31% less choice of where to purchase items
- 25% increased utility bills

Overall, 17% of BCUK said that they were financially impacted, 16% of LC respondents reported a loss of income and 13% reported increased costs.

9% of patients responding to the LUK 2021 survey reported that COVID-19 had caused them financial hardship.

Evidence of unmet needs

As lockdown lifts and shielding is paused, people living with blood cancer are less supported with their work situation, however many of the impacts of the pandemic on work have not disappeared and many who are clinically vulnerable remain fearful about increasing their social engagement. While the furlough scheme has been extended, there is an end date of September 30, 2021. People who cannot go on furlough or work from home are no longer advised to stay off work, and are not eligible for Statutory Sick Pay (SSP) or Employment and Support Allowance (ESA) only on the basis of being advised to shield.

6. Adolescent and Young Adult Patient Needs

Lymphomas are the most common cancers in teenagers and young adults (TYA) (15 to 24 years old). Government data⁶ based on cancers registered between 1997 and 2016 evidenced that 1 in 5 cancer cases in this group were lymphoma. Leukaemias were the fifth most common, with just under 1 in 10 cases. In many studies, patients aged 15-39 are defined as adolescent and young adults (AYA).

Barata et al. summarises much of the most recent literature (1): “*AYA experience unique needs and challenges related to quality of cancer care; physical health; peer and family relationships; educational attainment and employment; financial independence; concerns regarding dating, marriage, and fertility; body image; and health behaviours*”. However, these studies are not UK or blood cancer specific, and while there is likely to be crossover with the UK, recent relevant UK studies which have a haematological focus are limited.

The number of respondents to surveys run by BCA members and other blood cancer organisations illustrates some of the difficulties collecting data from TYA/AYA.

- Lymphoma Action 2016 16-34 - 3% (93)
- Leukaemia Care 2017 16-34 leukaemia patients - 4% (82)
- BCUK 2019 16-34 - 2% (31)
- Lymphoma Coalition 2020 18-39 - 5% (Approx. 33)
- ALAN 2019 Survey 18-39 - ALAN 12% (20)

A small England based study (Stevens et. Al, 2018) of 42 cancer patients aged 16-24, including 16 with leukaemia/lymphoma, identified the themes of: physical well-being, peer support, information, psychological and emotional support, education and employment, support for ‘those around you’ and cancer education and training for others. “*In all areas, patients would have liked more support than they actually received*”.

⁶ <https://publichealthmatters.blog.gov.uk/2021/03/15/cancer-in-children-and-young-people-what-do-the-statistics-tell-us/>

Summary of Survey Methodologies

Cancer Patient Experience Surveys

Wales 2016:

Seven health boards and one NHS trust participated in the survey, covering acute and specialist cancer care throughout Wales. All centres provided full lists of all eligible patients who had been admitted as an inpatient or day case. Eligible patients were defined as adults (aged 16 and over at the time of discharge) with a confirmed primary diagnosis of cancer, with an International Classification of Disease (ICD-10) code of C00-99 (excluding C44 and 84) or D05. 11,000 records were taken, compiled of patients who were discharged between June and December 2015. Fieldwork ran from 27th July 2016 - 26th October 2016 during this time. Respondents could either return the paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online using a unique login code. All survey materials were printed in both Welsh and English. Final number of responses was 6,514. <https://gov.wales/cancer-patient-experience-survey-2016>

Northern Ireland 2018:

Eligible patients were defined as adults (aged 16 and over at the time of discharge) with a confirmed primary diagnosis of cancer, with an International Classification of Disease (ICD-10) code of C00-99 (excluding C44 and 84) or D05. 6,256 records were taken, compiled of patients who were discharged between 1 May and 31 October 2017. Fieldwork ran from June 2018 - August 2018. Respondents could either return the paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online using a unique login code. Final number of responses was 3,478. <https://www.publichealth.hscni.net/sites/default/files/2019-01/Northern%20Ireland%20Cancer%20Patient%20Experience%20Survey%202018%20All%20Trusts%20Report.pdf>

Scotland 2018:

The national dataset was compiled from records of acute hospital activity to identify people aged 16 or over with an inpatient or day case record with any mention of cancer and a discharge date between 1 January 2017 and 30 September 2017. International Classification of Disease (ICD-10) code of C00-99 (excluding C44, 84 and D05). The total sample size was 8,302. Fieldwork ran from 19 September 2018 - 19 December 2018. Respondents could either return the paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online using a unique login code. Final number of responses was 5,001. <https://www.gov.scot/collections/scottish-cancer-patient-experience-survey/#2018survey>

Blood Cancer Alliance member surveys

Lymphoma Action 2016:

The respondents were all recruited from the England National Cancer Patient Experience Survey 2015 who had given consent to participate in follow-up research. Eligible patients had a lymphoma ICD10 code C810-14, C817, C819–27, C829-31, C833, C835, C837-89, C851-52, C857 or C859. The total sample size was 4,243. Fieldwork ran from 25 April 2016 - 15 July 2016. Respondents could either return the paper questionnaire (Freepost) or reply over the telephone via the Freephone helpline. Final number of responses was 3,380. <https://lymphoma-action.org.uk/sites/default/files/media/documents/2018-04/Understanding%20lymphoma%20as%20a%20cancer%20FINAL%20REPORT.pdf>

Leukaemia Care 2016:

The respondents were recruited through two arms. Arm 1: Leukaemia patients identified using England National Cancer Patient Experience Survey 2015, who had given consent to participate in follow-up research. Eligible patients had a leukaemia ICD10 code C901, C910-11, C913-C917, C919-22, C924-25, C928-31, C940, C944, C950-51 or C959. The total sample size was 1,711. Arm 2: An anonymous online survey of the wider blood cancer community - using an extended question set - and publicised through various online and print channels. Fieldwork ran from 26 September 2016 - 16 December 2016. Respondents could either return a paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online. Final number of responses was 2,019. <https://media.leukaemiacare.org.uk/wp-content/uploads/fullreport2016.pdf>

Leukaemia Care 2017:

The respondents were recruited through three arms. Arm 1: Leukaemia patients identified using England National Cancer Patient Experience Survey 2016, who had given consent to participate in follow-up research. Eligible patients had a leukaemia ICD10 code C901, C910-11, C913-C917, C919-22, C924-25, C928-31, C940, C944, C950-51 or C959. The total sample size was 1,680. Arm 2: 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. Fieldwork ran from 25 September 2017 - 15 December 2017. Respondents could either return a paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online. Final number of responses was 2,884. <https://media.leukaemiacare.org.uk/wp-content/uploads/Living-with-Leukaemia-2018-Full-Report-Web-Version.pdf>

Blood Cancer UK 2019:

The respondents were recruited through two arms. Arm 1: blood cancer patients identified using England National Cancer Patient Experience Survey 2018, who had given consent to participate in follow-up research. The sample was reflective of proportion of leukaemia, NHL, HL and myeloma (and plasmacytoma) diagnoses in the UK each year. Eligible patients had ICD10 code: C810, C811, C812, C814, C817, C819, C820, C821, C822, C823, C824, C825, C826, C827, C829, C830, C831, C833, C835, C837, C838, C839, C851, C852, C857, C859, C900, C901, C902, C903, C910, C911, C913, C914, C915, C916, C917, C919, C920, C921, C922, C923, C924, C925, C927, C928, C929, C930, C931, C942, C943, C944, C946, C950, C959. The total sample size was 1,972. Arm 2: an anonymous online survey specifically for those on watch and wait who are not captured by CPES. This was promoted via social media and Blood Cancer UK's networks. Fieldwork ran from 28 August to 18 October 2019. Arm 1 respondents could either return a paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online. Arm 2 respondents could reply over the telephone via the Freephone helpline or complete online. Final number of responses was 1,430 from Arm 1 and 204 from Arm 2.

Blood Cancer UK 2020:

Respondents were recruited through via BCUK channels (including social media accounts and newsletters) and it was promoted by several other organisations. Fieldwork launched in late March 2020. Data used was collected between 27 March and 13 July 2020. Over 6,400 responses.

Leukaemia Care 2020:

CLL patients were invited to respond to the survey via emails from the two charities and newsletters over a two-week period. Survey 1 was collecting data between 28th March and 17th April 2020. Survey 2 was collecting data between 20th April and 19th May 2020. Survey 3 was collecting data between 20th May and 31st May 2020. Final number of responses was 2,762 (844 survey 1, 842 survey 2, 1,076 survey 3).

Leukaemia UK 2021:

An online panel survey and open survey sent to Leukaemia UK supporters. There was a YouGov panel survey and a shorter survey sent through mailing list and social media. Data was collected between 15th April and 18th May 2021. Final number of responses through the YouGov survey was 509 respondents: 225 blood cancer patients, 284 friends or family of someone diagnosed with blood cancer. There were 89 respondents to the open survey.

Additional blood cancer surveys

CML Advocates Network 2018:

Respondents were recruited through CML patient associations via online forums, social media and other methods. The survey available exclusively online. The questionnaire was made available in eleven languages: Arabic, Danish, English, Finnish, French, German, Hebrew, Italian, Japanese, Russian and Spanish. Fieldwork ran from 14 March to 1 August 2018. Final number of responses was 1016, covering 68 countries. Final number of responses from the UK was 45.

Acute Leukemia Advocates Network 2019:

Respondents were recruited through ALAN network, via email, online forums, social media and other methods. The survey available exclusively online. The questionnaire was made available in nine languages: Chinese (Simplified), English, French, German, Hebrew, Italian, Portuguese (Brazilian), Russian and Spanish. Fieldwork ran from 4 February to 22 November 2019. Final number of responses from was 552, covering 42 countries. Final number of responses from the UK was 168.

Lymphoma Coalition 2020:

Respondents were recruited through ALAN network, via email, online forums, social media and other methods. The survey available exclusively online. The questionnaire was made available in eighteen languages: English, Arabic, Bulgarian, Chinese, Dutch, Finnish, French, German, Hindi, Italian, Japanese, Korean, Lithuanian, Portuguese, Punjabi, Serbian, Slovak, Spanish and Swedish. Fieldwork ran from 13 January to 13 March 2020. Final number of responses from the UK was 679.

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