

Leukaemia Care Living with Leukaemia

YOUR Blood Cancer Charity

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Background

The Cancer Patient Experience Survey (CPES) is commissioned by NHS England annually. However, blood cancers differ from solid tumours, including the fact that some are treatable yet incurable, so are more like a chronic illness than traditional views of "cancer". Interactions with patients (via our helpline, website and support groups for example) suggest they face challenges unique to those with a blood cancer diagnosis.

Methodology

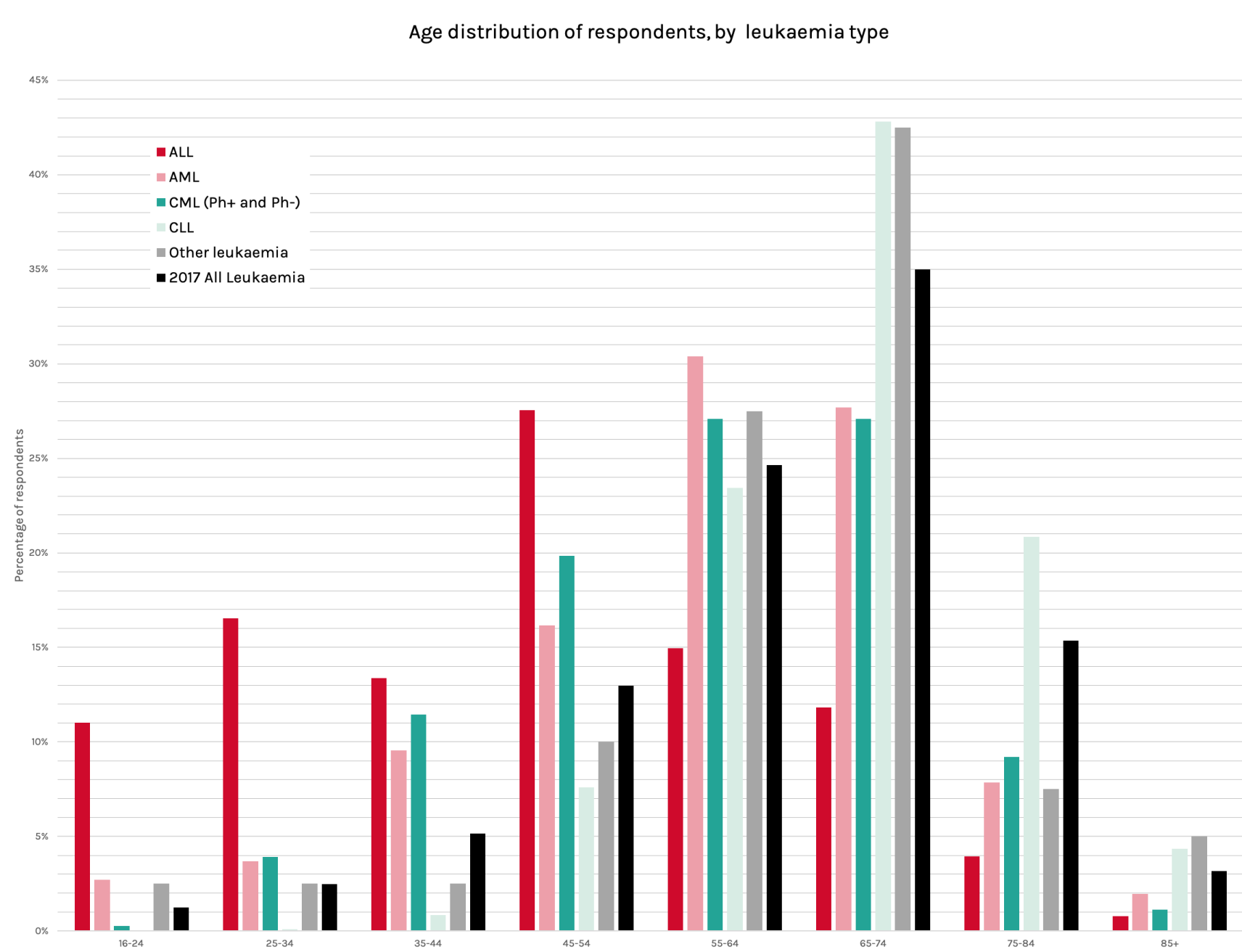
From September to December 2017, Leukaemia Care undertook the second Living with Leukaemia survey to identify and quantify unmet needs of blood cancer patients. The first was undertaken in 2016.

There were three arms of recruitment:

- Contacting those who consented following CPES completion (1205 responses)
- The Leukaemia Care database (508)
- Anonymous respondents (616)

Additionally:

- **55%** of respondents were male and 45% female.
- **91%** were from England and 7% from the rest of the UK.



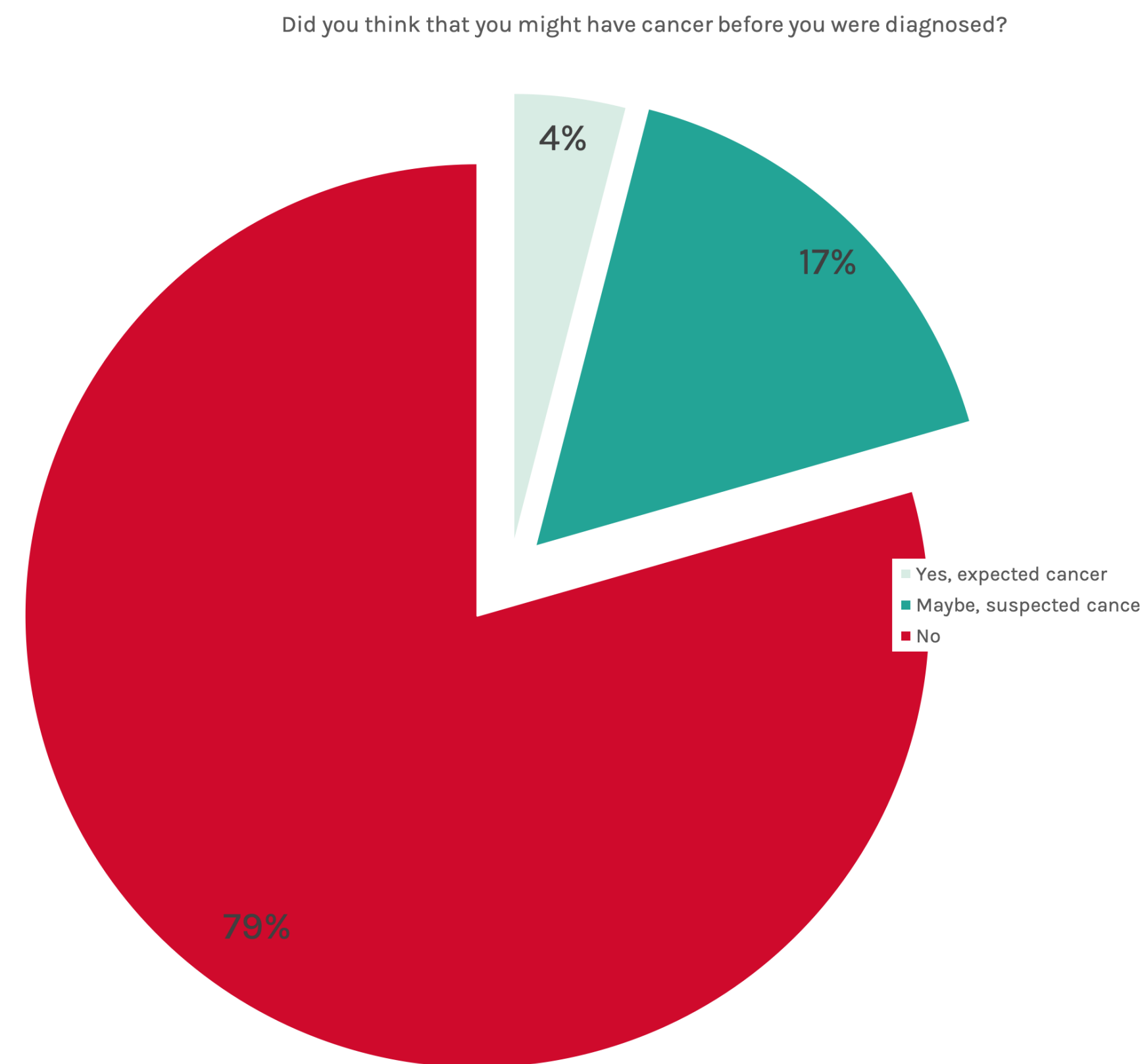
Results

Blood cancer diagnosis	Number of respondents
Acute lymphoblastic leukaemia (ALL)	147
Acute myeloid leukaemia (AML)	443
Chronic lymphocytic leukaemia (CLL)	1152
Chronic myeloid leukaemia (CML)	374
Other leukaemia	224
TOTAL	2329*

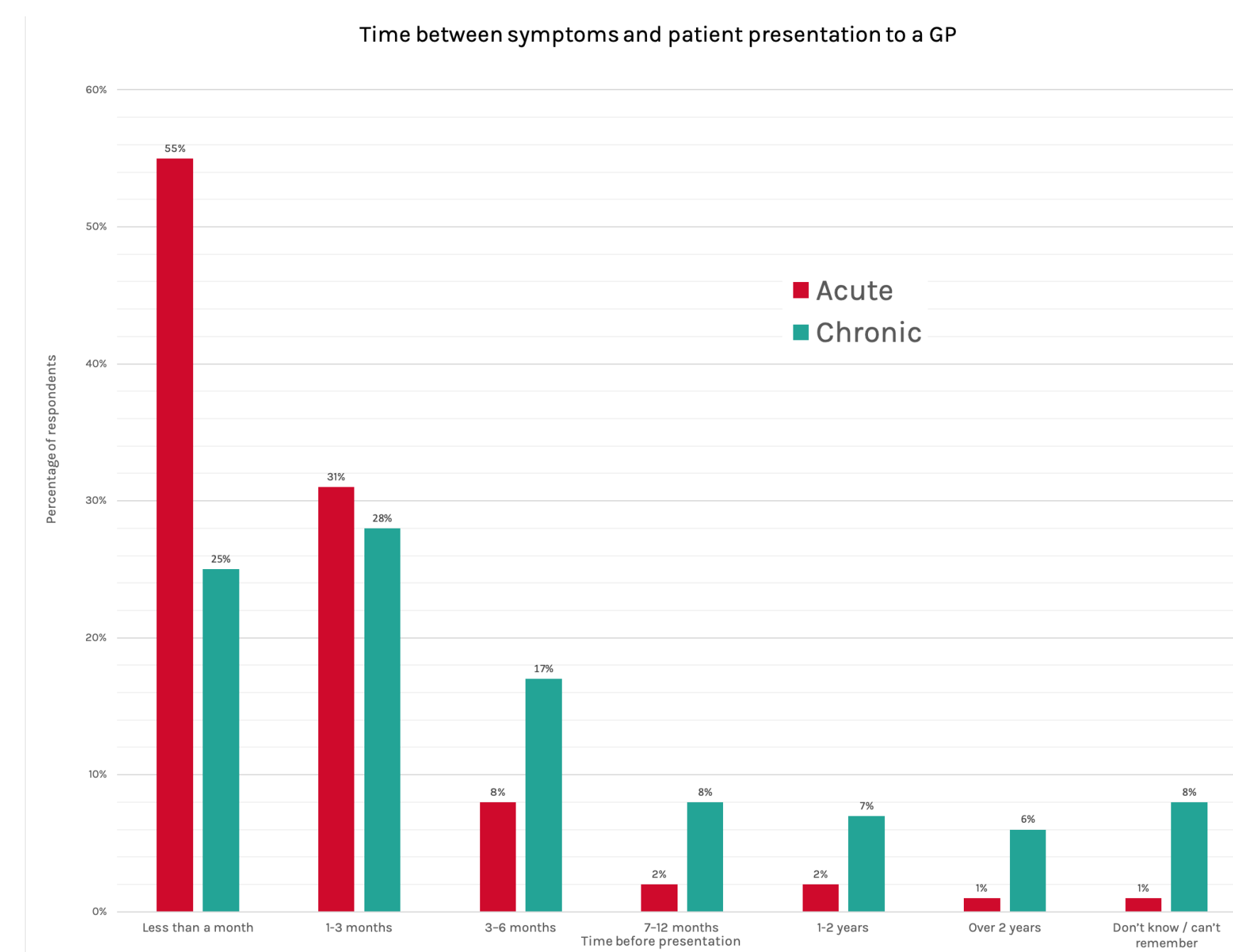
*the total is higher than the overall number of responses due to some people indicating they had more than one type of leukaemia.

Diagnosis

The survey identifies several issues relating to awareness and early diagnosis of leukaemia.



Despite **85%** of patients experiencing symptoms, few expected or suspected cancer.

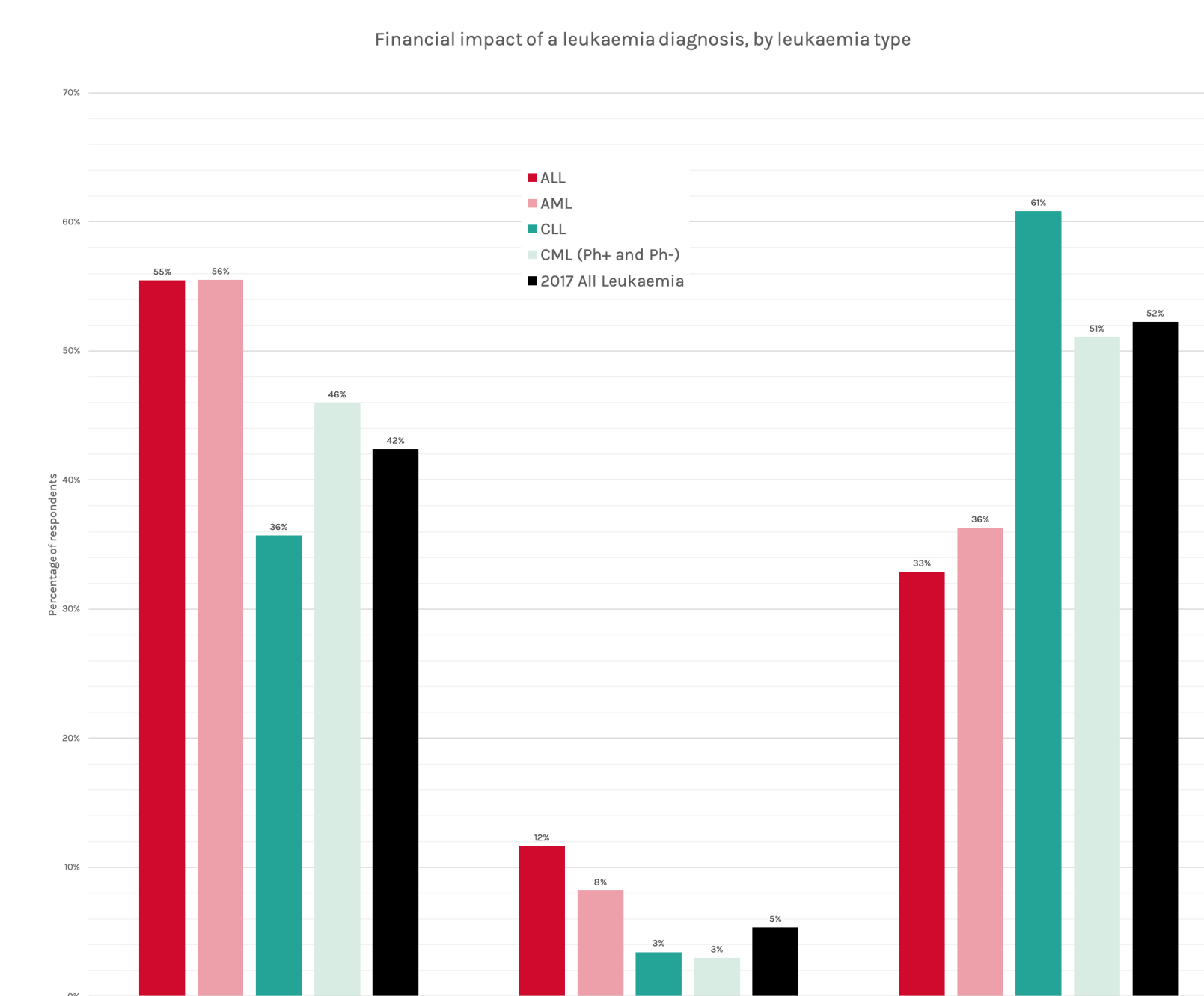


As well as some patients waiting a long time to see a doctor, there are also delays in diagnosis once contact has been made.

15% of all patients visited their GP 3 or more times before diagnosis. It is a particular issue for acute patients, with **27%** of ALL and **23%** of AML patients reporting being treated for another condition first. All these statistics show little improvement since the 2016 survey.

Less than half of respondents (**48%**) felt their GP had a complete understanding of blood cancer, and this has also not improved over time (if examined according to year of diagnosis, from before 2010 until 2017).

Finances



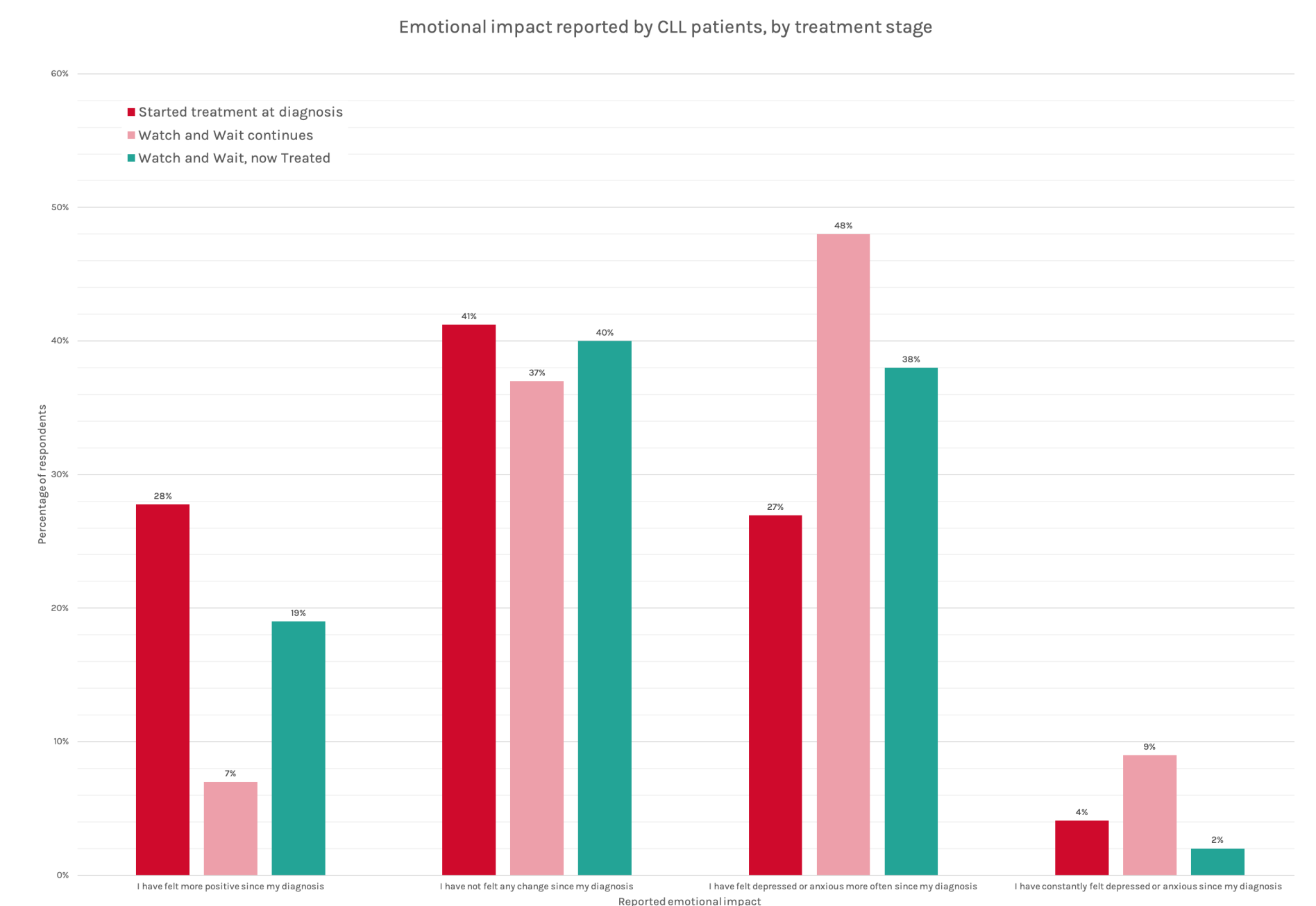
As shown above, patients experience a negative financial impact following diagnosis, especially acute patients. They are more likely to report stopping work or education (acute **79%** vs chronic **33%**), whereas chronic patients are more likely to report reducing their hours (**23%** chronic vs **14%** acute) or continuing as normal (**7%** acute v **45%** chronic).

This negative impact is due to both loss of income (experienced by **70%** of patients) and increased costs (**64%**). Support and advice on finances was received by only **61%** of leukaemia patients.

Emotional Impact

45% of patients report feeling depressed and/or anxious more often since their diagnosis. Those still on watch and wait, who have relapsed or are living with dependent children are more likely to report a negative impact.

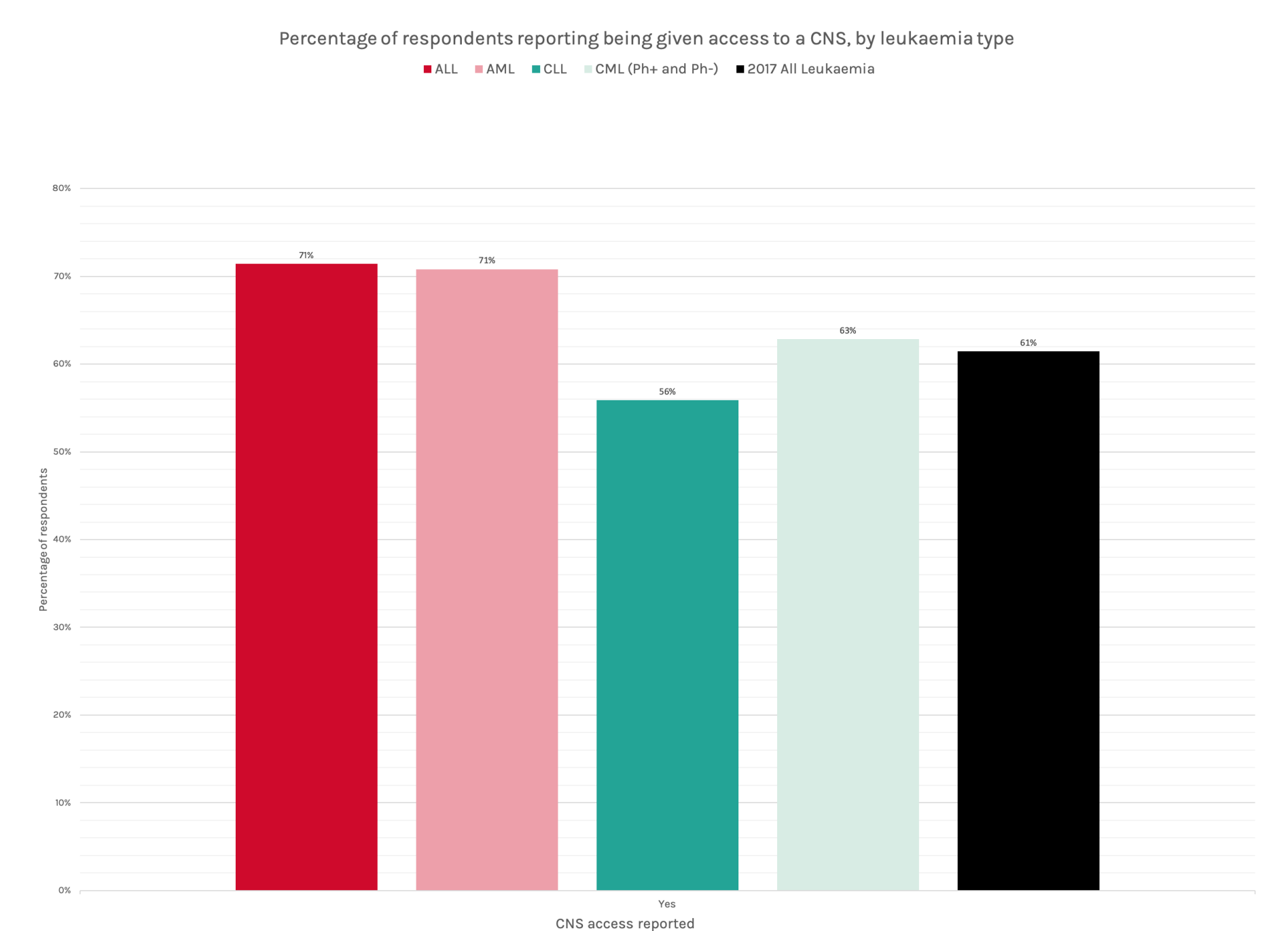
Only **46%** of all patients surveyed received information on emotional support, despite **96%** wanting information.



The watch and wait period was identified as concerning or worrying by **53%** of CLL patients, and only **66%** received written information about it. There was a correlation between receiving understandable information on watch and wait and feeling less concerned or worried.

Clinical Nurse Specialists

CPES identifies CNS access as the most powerful positive influence on a cancer patient experience.



This is a particular issue for CLL patients.

61% of those who started treatment straight away had access, compared to **54%** of those on watch and wait at diagnosis, for those still on watch and wait this drops to **29%**.

Conclusion

As a result of the survey, we make three recommendations:

1. Work should continue to improve awareness of the symptoms of blood cancers, among the public and primary healthcare professionals.
2. Support and advice on finances should continue to be provided, including signposting to specialist organisations.
3. The psychological needs of patients need increased recognition and all patients should be offered support. This should include access to a CNS.



Access the full report.

With special thanks to Quality Health and all the patients who took part in the survey.