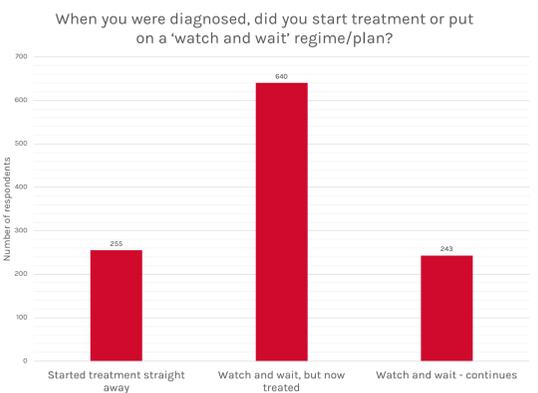




Background:
 A cancer diagnosis can have negative effects on a patient's mental health. Watch and wait (WW), or active monitoring, is a common course of action for chronic lymphocytic leukaemia (CLL) patients. WW has been identified as a particular source of distress for CLL patients. Evans et al. (2011) conducted interviews with CLL patients and found that those on WW were as likely to experience depression and anxiety as those in active treatment.

Methods:
 The survey asked questions about the patient experience following a CLL diagnosis, including a section on watch and wait. The survey was available to complete as a paper questionnaire or via an online link. 1152 CLL patients responded to the survey. To the best of our knowledge, this is the largest ever CLL patient survey run by a charity. 97% were from the UK.



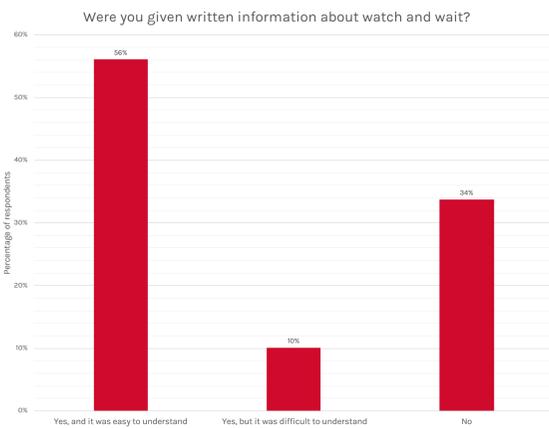
Aims:
 Leukaemia Care conducted a survey of CLL to identify and quantify the issues CLL patients face, particularly those patients on watch and wait (WW).

Conclusion:
 This survey highlights areas of need to reduce the psychological impact of a CLL diagnosis. There is a need to improve communication at diagnosis, including a tailored explanation of CLL and the rationale for WW, providing high quality written information to take away. The findings suggest that patients on WW need support, such as CNS access, as much as those starting treatment.

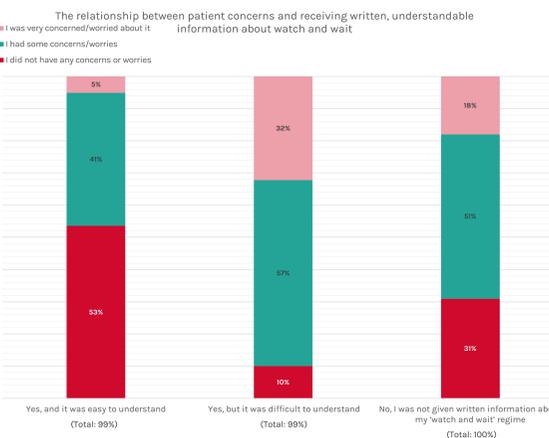
Results: Understanding CLL and watch and wait
 At diagnosis, only 66% of all respondents fully understood CLL was a cancer and only 42% said they fully understood what was wrong with them. Patients placed on watch and wait were more likely to be unaccompanied at diagnosis (49%) than those who started treatment (38%).

Of those on watch and wait at diagnosis, only 60% fully understood the reasons for being placed on watch and wait (decreases to 49% for those still on watch and wait at time of survey).

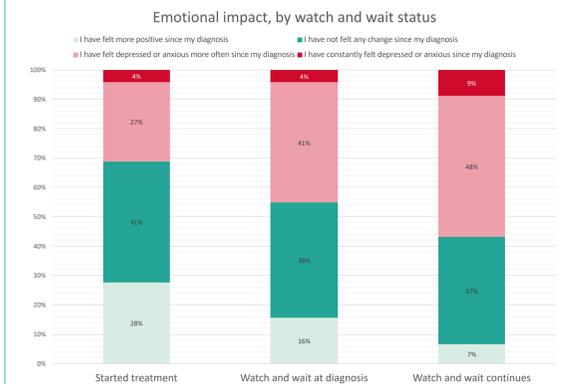
53% said they had concerns or worries about watch and wait. The majority (66%) of patients in the UK are given written information about watch and wait.



There was a correlation between feeling worried and being given understandable information regarding watch and wait.

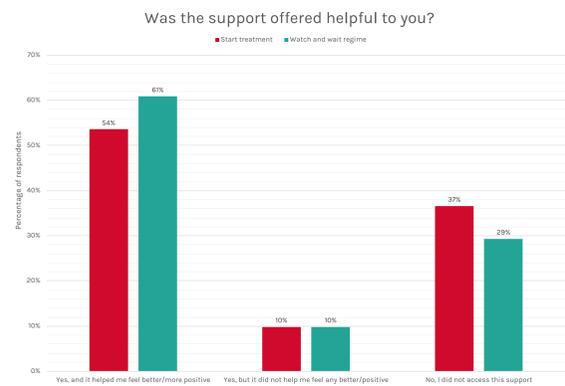


Emotional impact of watch and wait
 Comparison with responses from other leukaemia patients suggests CLL patients are the least likely to be affected emotionally by their diagnosis. However, certain groups of CLL patients are more likely to be emotionally affected by their diagnosis than the overall figure suggests.



The number of CLL patients still on watch and wait who are reporting feeling depressed or anxious more often since diagnosis (57%) is equivalent to the highest level of emotional impact reported by patients with any leukaemia type (in other Leukaemia Care surveys).

Support provision
 Patients placed on watch and wait at diagnosis are less likely to be given information on emotional support than those starting treatment (38% vs. 42%), reducing to 29% for those still on watch and wait. Those on watch and wait at diagnosis were also less likely to be offered additional support (such as support groups, buddy schemes or counselling) than those starting treatment straight away (61% vs. 69%), reducing to 39% for those still on WW.



Access to a clinical nurse specialist (CNS) has been identified by NHS England as a key driver of improved patient experience, yet the majority of CLL patients do not have access.

