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CLL Support Association

Living with CLL

Results from the quality of life survey
among CLLSA members

September 2014

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Overview

- A survey was conducted by CLLSA to better understand the impact CLL has on quality of life (QoL)
- The survey consisted of four open questions
 1. How long have you been diagnosed with CLL?
 2. If you are still in 'watch and wait' what have been the key issue/s that have most affected your quality of life?
 3. If you have had treatment, please indicate the nature of the treatment
 4. Post-treatment, what have been the issues that have most affected your quality of life?
- A quantitative analysis has been conducted to identify trends in the survey results

Executive summary



282

CLLSA members completed survey



1.5.....288 months

Length of time respondents had been living with CLL

84%



of all respondents reported a negative impact of CLL on their quality of life



Anxiety

was the most frequently reported **emotional** issue



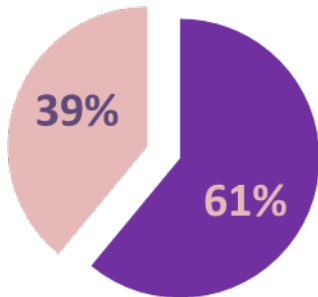
Fatigue

was the most frequently reported **physical** issue for those in watch and wait



Infections

was the most frequently reported **physical** issue for those post treatment



Respondents by patient type

- Watch and wait*
- Post-treatment**

*'Watch and wait' is a term often used to describe both the period of time before treatment initiation, as well as after a course of treatment has ceased. For the purpose of analysis, watch and wait only refers to those who have not yet taken treatment
**Post-treatment statistics also include those who are currently on treatment

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Executive summary



Watch and wait

173 people in watch and wait

86%

respondents in watch and wait reported a negative impact of CLL on their quality of life



Anxiety

was the most frequently reported **emotional** issue with 85% of respondents reporting this issue

zzz **Fatigue**

was the most frequently reported **physical** issue with 72% of respondents reporting this issue. **Post treatment this decreased to 47%**



Post treatment

109 people post-treatment

81%

respondents post-treatment reported a negative impact of CLL on their quality of life



Anxiety

issues **decreased** post treatment with **51%** reporting these issues

zzz **Fatigue**

decreased post treatment with **47%** of respondents reporting this issue



Infection & immune system issues

were the most reported **physical** issues with **49% of post-treatment** respondents reporting these issues compared to **36% of the watch and wait patients**

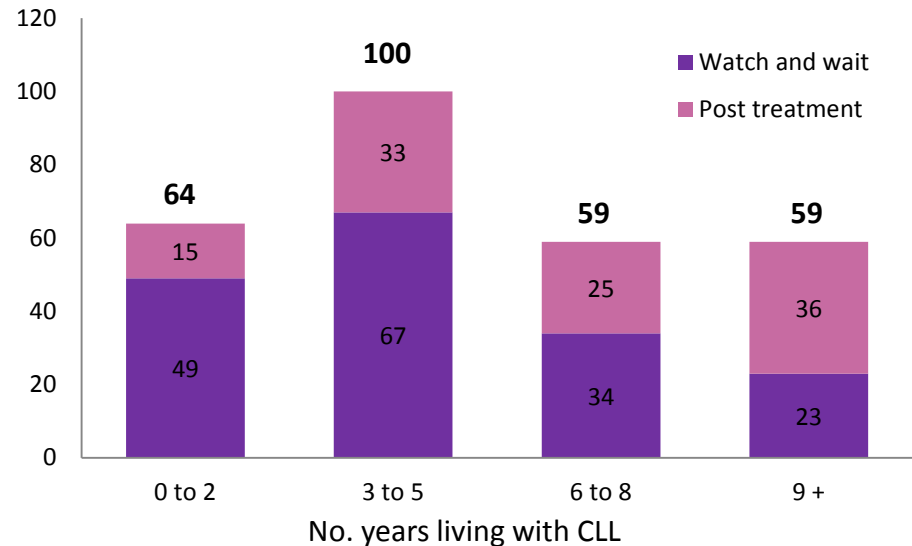


Who completed the survey

No. of respondents who are in pre treatment watch and wait vs. post-treatment



No. of years respondents have been living with CLL



Insights

- Of the 282 respondents, 61% had not yet taken any treatment for their CLL
- The length of time respondents had been living with CLL ranged from 1.5 months to 288 months (24 years)

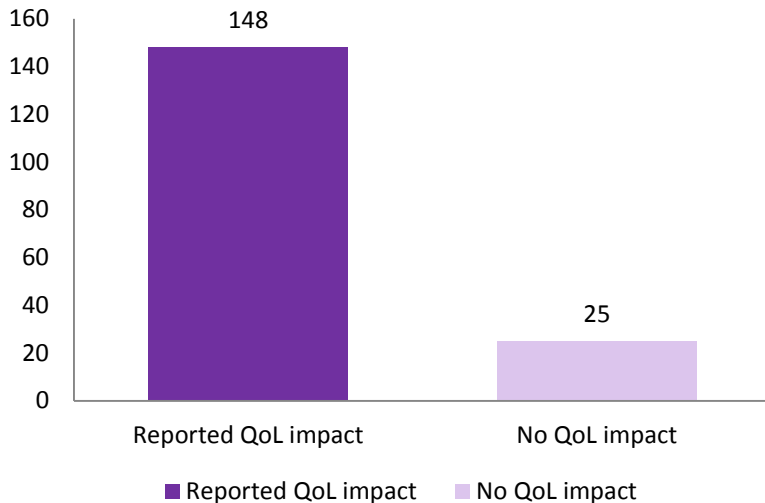
Reported QoL impact for **pre-treatment watch and wait patients**

- The following slides are an analysis of responses to question 2: if you are still in watch and wait what have been the key issues that have most affected your quality of life?

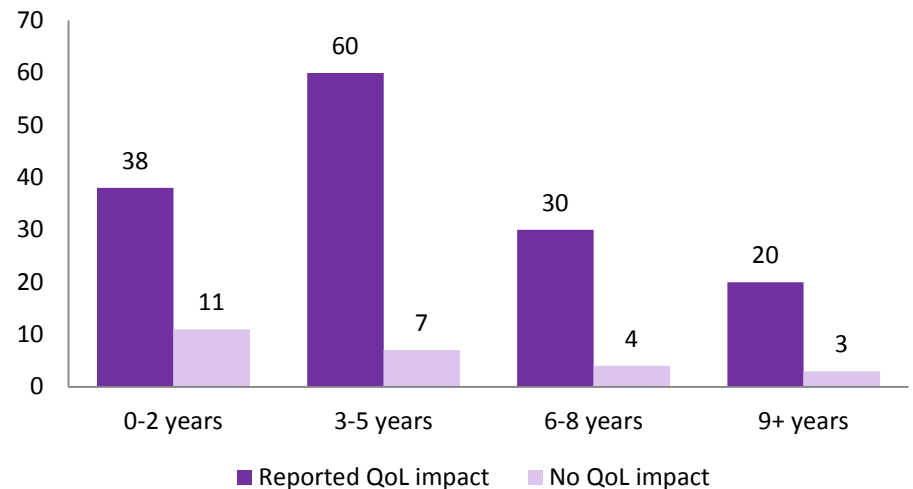


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No. of the **173** respondents who reported an impact on their QoL whilst still in watch and wait due to living with CLL



No. of the **173** respondents who reported an impact on their QoL by length of time living with CLL



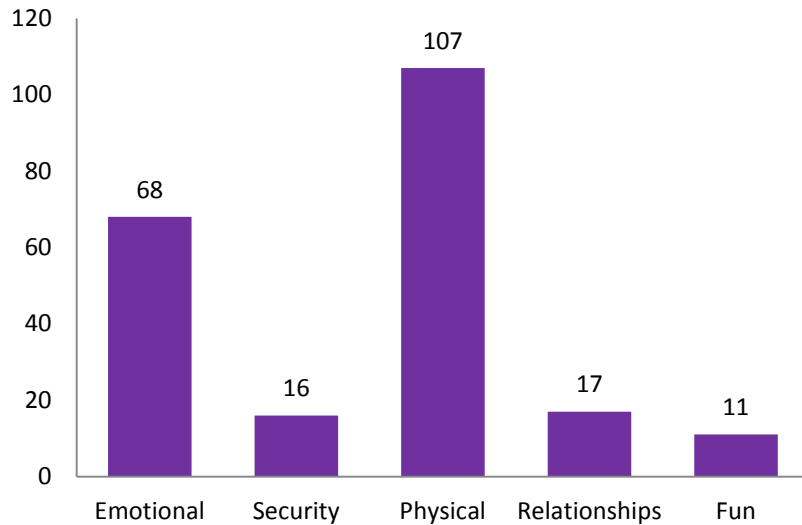
Insights

- 86% respondents still in watch and wait reported a QoL impact due to CLL
- This varied from 78% to 90% depending on the length of time the respondent had been living with CLL with the highest incidence reported at 3-5 yrs (78% 0-2 yrs, 90%, 3-5 yrs 88% 6-8yrs, 87% 9+ yrs)

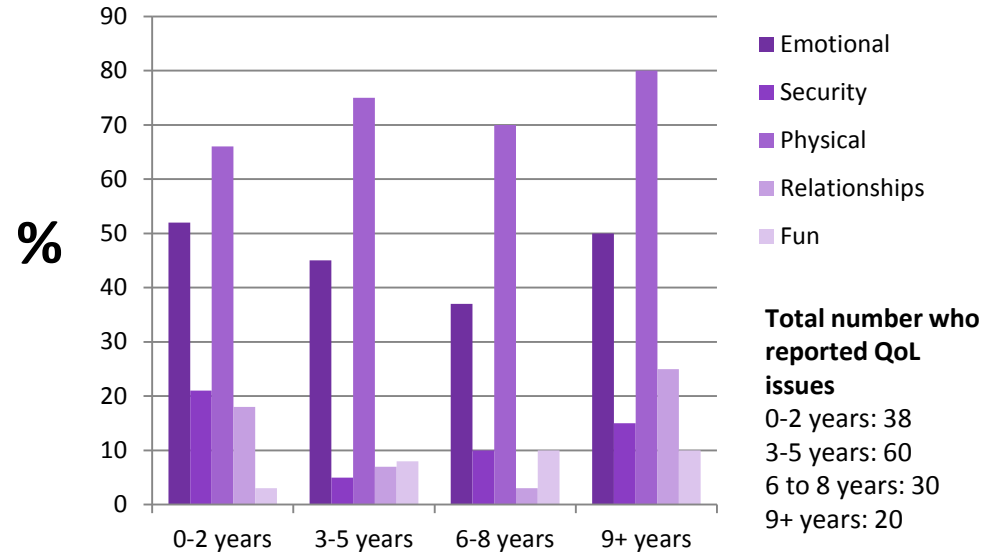


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Type of QoL issues the 148 respondents have experienced during watch and wait



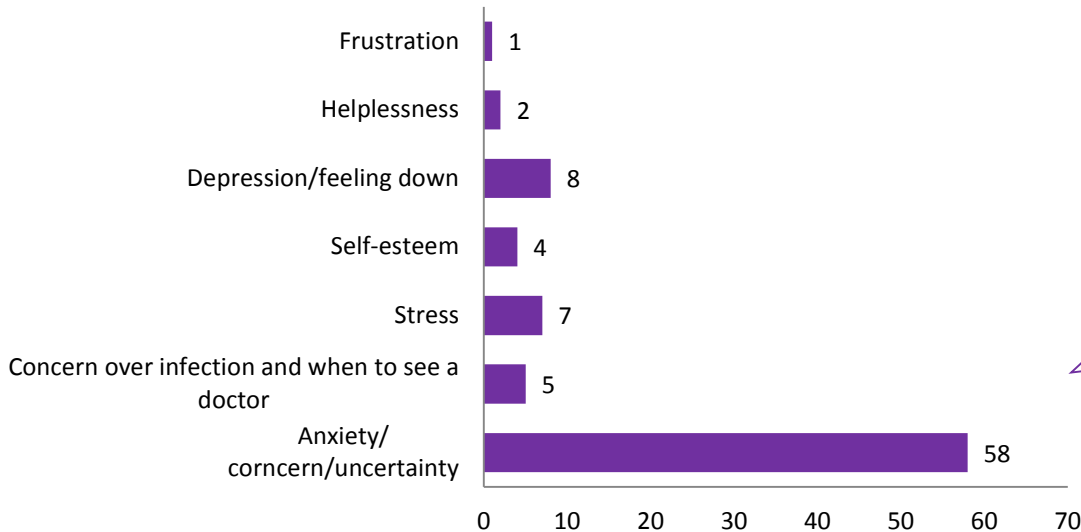
Percentage of respondents who reported QoL issues by length of time living with CLL



Insights

- Overall, the incidence of physical QoL issues was highest among respondents (72%) followed by emotional quality of life issues, which affected nearly half of respondents (46%)
- Incidence of physical QoL issues increased with length of time living with CLL from 66% at 0-2 yrs to 80% at 9+ yrs
- Incidence of emotional QoL issues was highest among the 0-2 yrs group (52%), this was also high among the 9+ yrs group (50%)

Breakdown of the emotional wellbeing issues the 68 respondents have experienced during watch and wait



Not sure what the future holds
0-2 yrs

The uncertainty. Not knowing when it will kick in
3-5 yrs

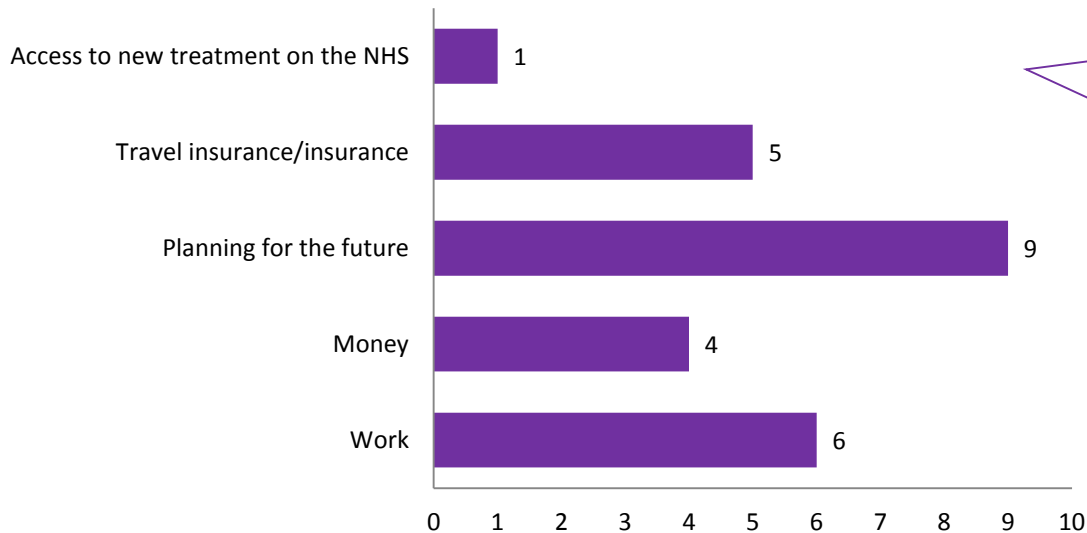
Nagging uncertainty about other health issues which may or may not be connected with the CLL
6-8 yrs

The dread of every hospital appointment to find out whether it's got worse. I wonder whether I would have rather not known as I've not needed any treatment for 10 years
9+ yrs

Insights

- 85% of respondents stated experiencing anxiety, concern or uncertainty about living with CLL
- Anecdotal responses suggest that the same anxiety is felt regardless of the period of time living with CLL

Breakdown of the security issues the 16 respondents have experienced during watch and wait



Lack of money as I can only work part-time
0-2 yrs

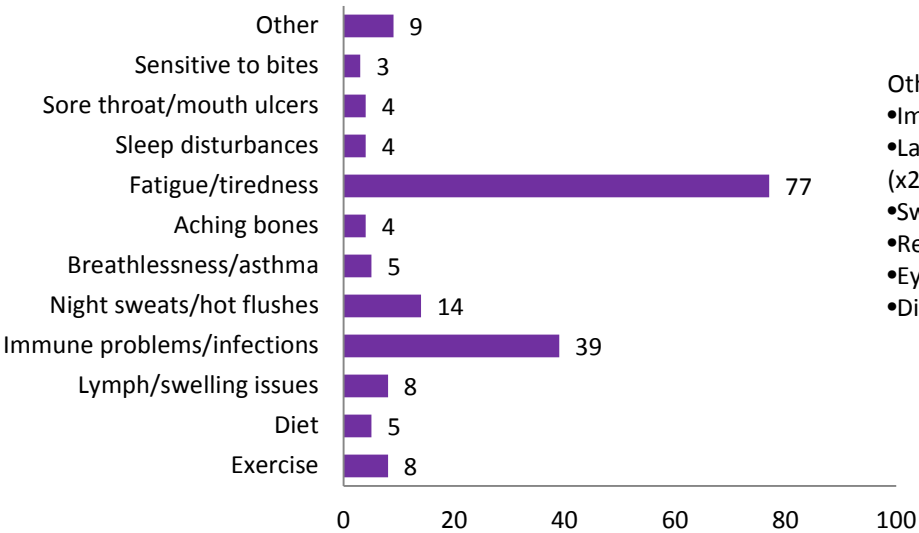
Just worrying, not telling family or children, trying to plan financially for the future
3-5 yrs

Attitude of others not understanding or listening to me at work. The attitude that if you are not receiving treatment you are not feeling ill. I was diagnosed because I was not feeling well, those feelings have not changed being on watch and wait
9+ yrs

Insights

- Planning for the future was the most frequently reported security issue (56%) followed by work related issues (38%)
- 31% of respondents reported an increase in travel insurance/insurance costs

Breakdown of the physical issues the 107 respondents have experienced during watch and wait



Other =

- Impotency (x2)
- Lack of concentration/brain changes (x2)
- Swollen spleen (x2)
- Restless leg syndrome
- Eye sight issues
- Difficulty passing urine

Extreme fatigue, dealing with/trying to avoid infections and trying to explain to people the reason I am not having treatment
0-2 yrs

Tiredness, night sweats and colds and coughs that take months to go away
3-5 yrs

Lately finding it takes longer to get back to a normal energy levels after a busy day – a night's sleep isn't enough
9+ yrs

Insights

- The incidence of fatigue and tiredness was highest among respondents (72%) followed by immune problems and infections (36%)

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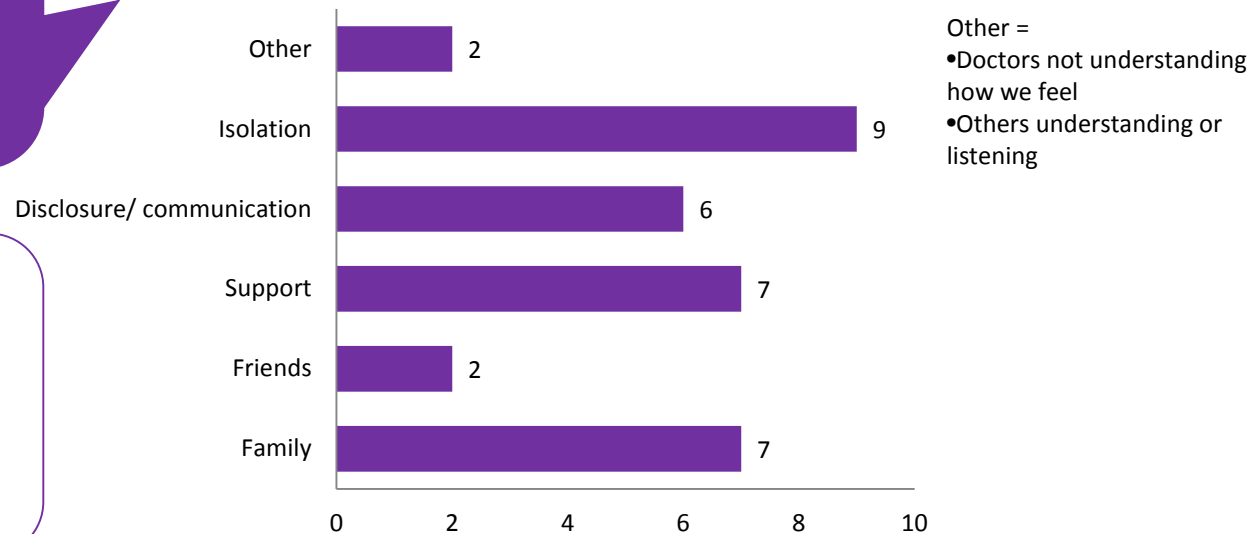
Feel isolated. Coming to terms with diagnosis. Managing the seriousness of the diagnosis. Knowing when to seek GP advice such as with heavy cold due to concerns about infection. Feel something could be done to help newly diagnosed patients

0-2 yrs

Whom to tell, anxiety, feelings of helplessness, being told you have a potentially life threatening illness, which is 'nothing to worry about' and being told to 'go away and we'll see if anything happens'

6-8 yrs

Breakdown of the relationship issues the 17 respondents have experienced during watch and wait



Insights

- The incidence of feelings of isolation was highest among respondents (53%) followed by lack of support (41%) and impact on family relationships (41%)
- 35% respondents found disclosure or communicating about CLL an issue

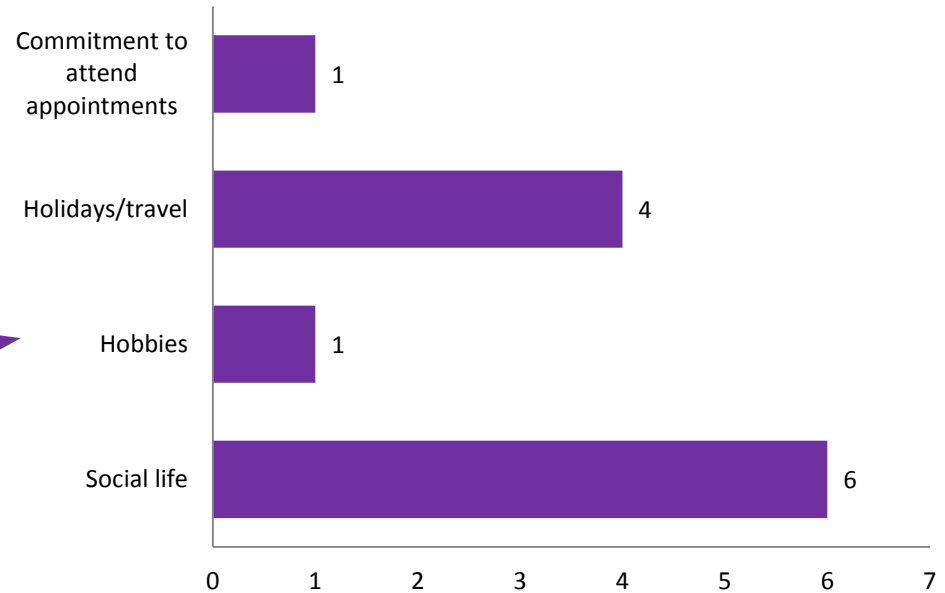
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General feeling of tiredness. If I do a lot today I know I will need to rest tomorrow.
Avoiding social gatherings to avoid infection
3-5 yrs

Fatigue, infections, avoiding crowded places, having to be aware of hygiene of places and other people when outside. Having to miss out socially especially through the winter months
6-8 yrs

Breakdown of the fun impact the 11 respondents have experienced during watch and wait



Insights

- The incidence of impact on social life was highest among respondents (55%) followed by an impact on travel and holidays (36%)

Reported QoL impact for **post-treatment** patients

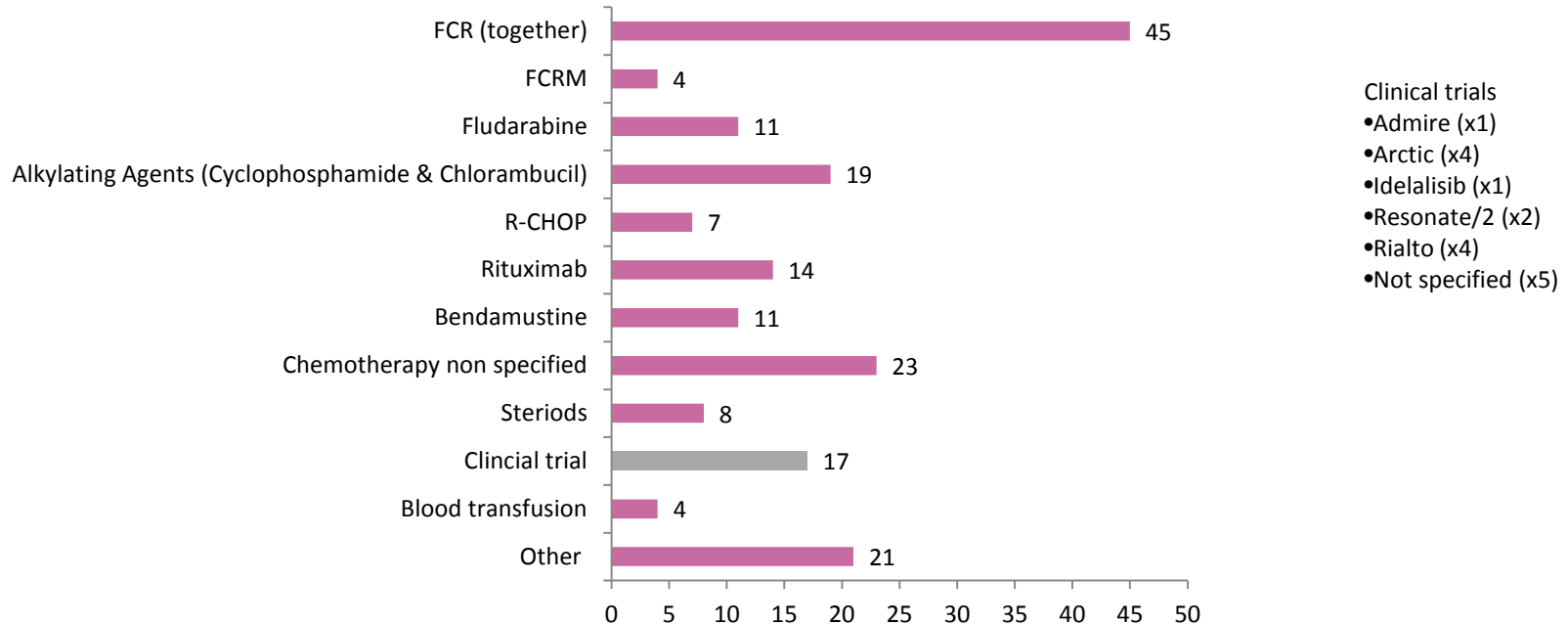
- The following slides are an analysis of responses to questions 3: if you have had treatment, please indicate the nature of the treatment; and 4: post-treatment, what has been the issue/s that have most affected your quality of life?



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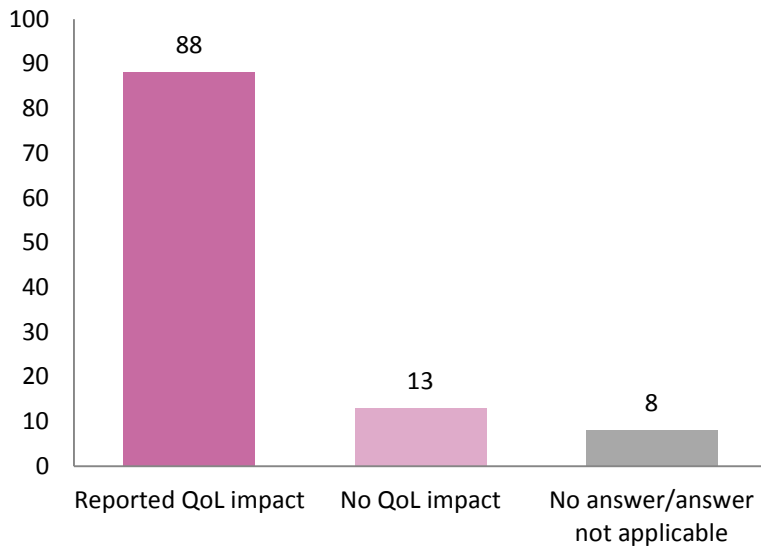
Breakdown of the treatments received by the 109 respondents in the 'post-treatment' category



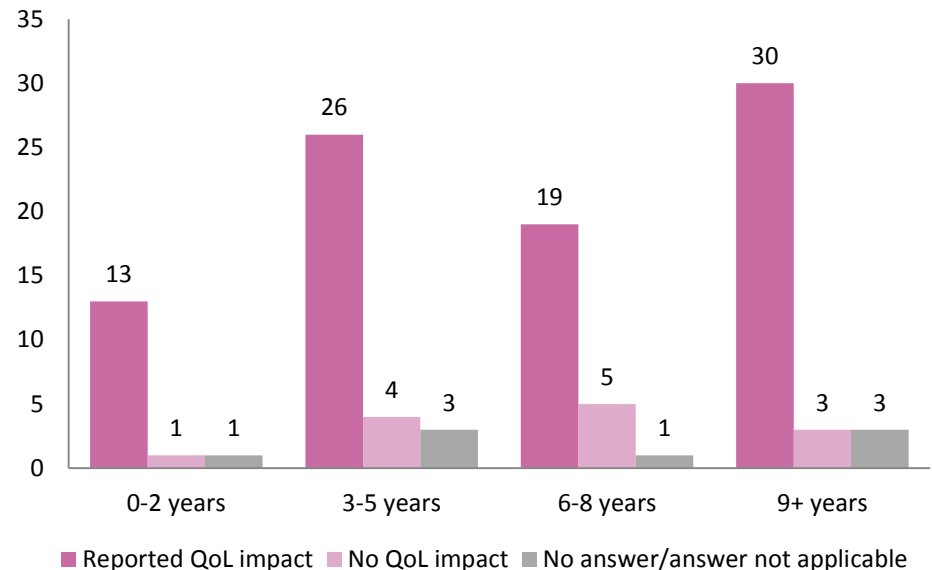
Insights

- Combination treatment (Fludarabine, Cyclophosphamide, Rituximab) was taken by the highest number of respondents (49%) followed by a non-specified chemotherapy (21%)

No. of the 109 respondents who have reported an impact on their QoL post-treatment



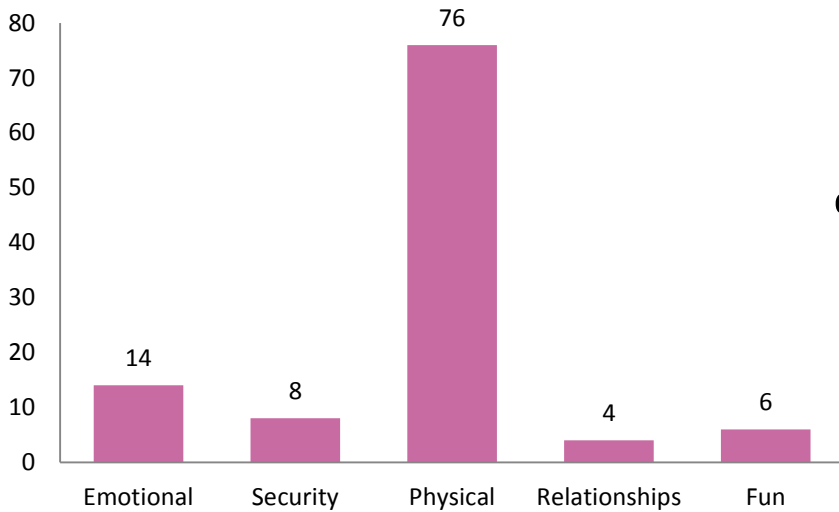
No. of the 109 respondents who reported an impact on their QoL by length of time living with CLL



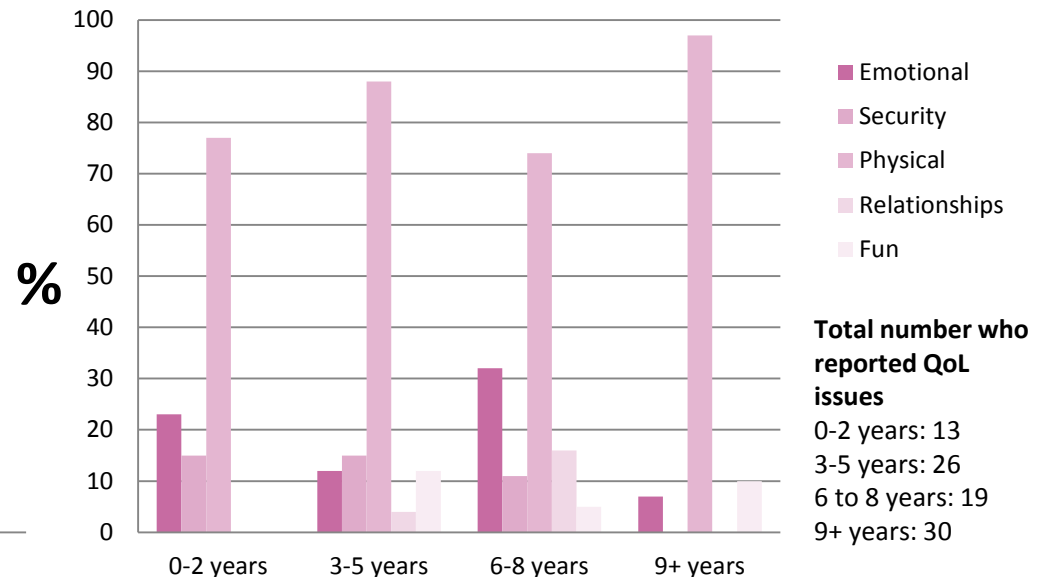
Insights

- 81% respondents post-treatment reported a QoL impact due to CLL
- This varied from 76% to 87% depending on the length of time the respondent had been living with CLL with the highest incidence reported at 0-2 years (87% 0-2 yrs, 79%, 3-5 yrs, 76% 6-8yrs, 83% 9+ yrs)

Breakdown of the types of quality of life issues the 88 respondents have experienced post-treatment



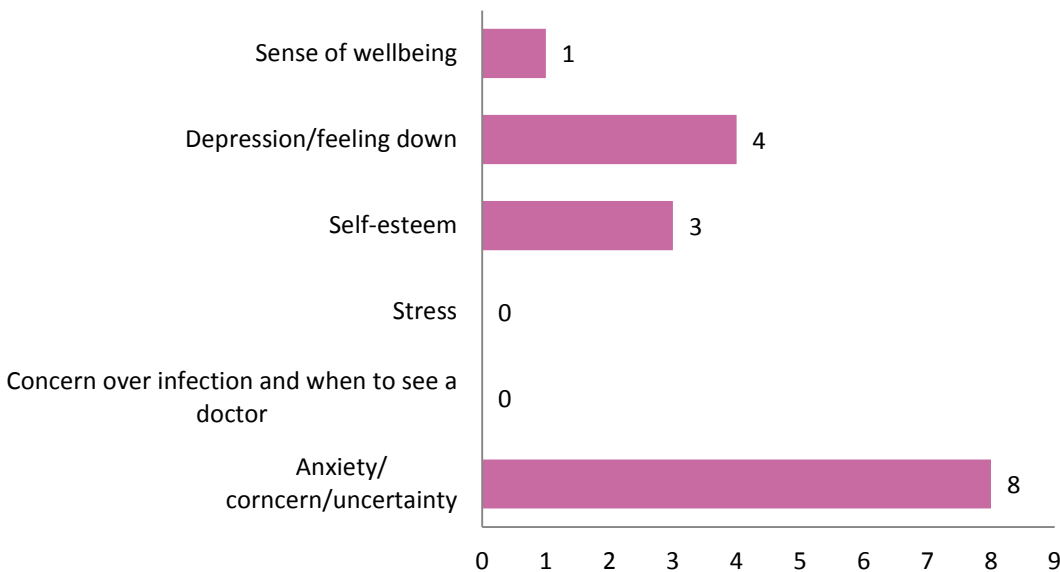
Percentage of respondents who reported QoL issues by length of time living with CLL



Insights

- Overall, the incidence of physical QoL issues was highest among respondents (86%) followed by emotional quality of life issues (16%)
- Incidence of physical QoL issues increased with length of time living with CLL from 77% at 0-2 yrs to 97% at 9+ yrs
- Incidence of emotional QoL issues was highest among the 6-8 yrs group (32%), this was also high among the 0-2 yrs group (23%)

Breakdown of the emotional wellbeing impact the 14 respondents have experienced post-treatment



Difficult to recover from chemo and feel able to get back to normal and then to feel confident to go out and try and find a job!

*Clinical trial patient (Arctic Trial)
0-2 yrs*

Fear of recurrence

Chemotherapy patient, 3-5yrs

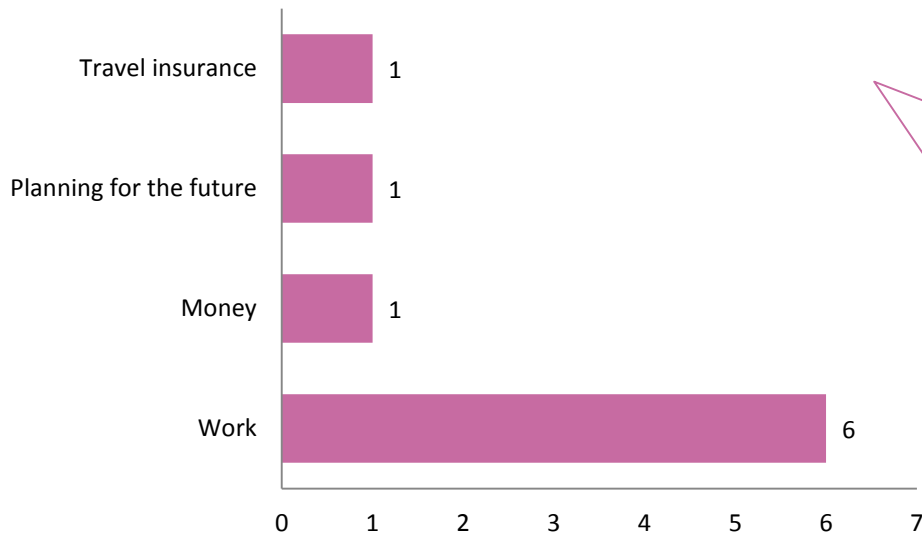
Fear of the disease getting worse

Forsivel patient, 9+ yrs

Insights

- 57% of respondents reported experiencing anxiety, concern or uncertainty about living with CLL
- No respondents felt stressed or concerned about when to see a doctor regarding infections

Breakdown of the security impact the 8 respondents have experienced post-treatment



Not being able to work. I was 36 when diagnosed and I have now lost my job

FCR patient, 0-2 yrs

I was unwell having frequent chest infections for a year post-treatment. I found it difficult to continue working, it was very disappointing and I was often exceedingly fed up that it took that amount of time to start to feel 'normal'. In my case the GPs were particularly unsympathetic and therefore not particularly helpful, they had a lack of knowledge about CLL and the effects of 6 months of chemotherapy

Chemotherapy patient, 3-5 yrs

Insights

- The incidence of work related issues was highest (86%) among respondents

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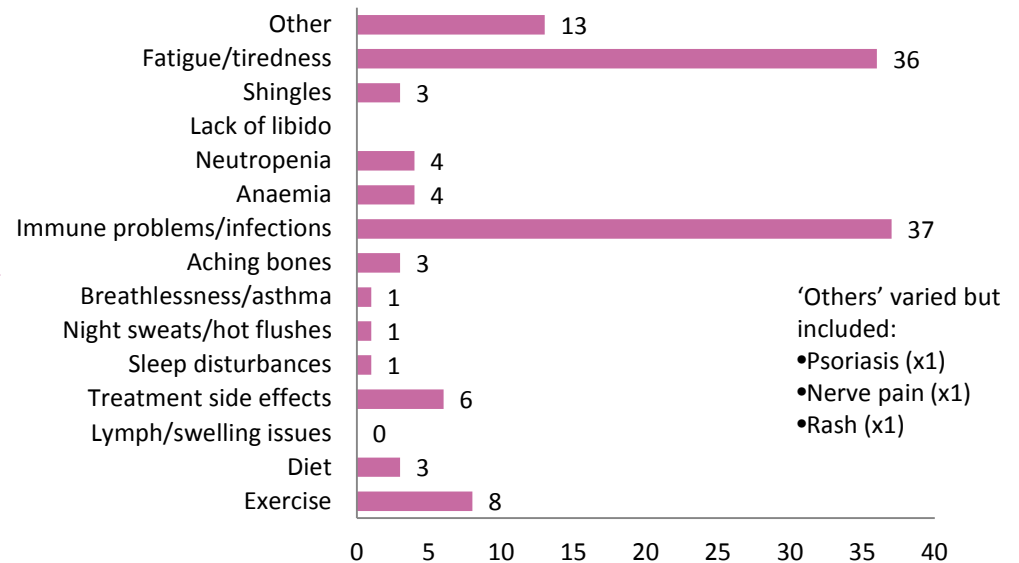
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Nearly all symptoms resolved, had a flare up of Psoriasis in Dec 2013 (first diagnosed in 2005). Psoriasis is worse after CLL treatments and during cold weather
Clinical trial patient (Idelalisib), 3-5 yrs

Having pneumonia after chemo makes it difficult to do the things I used to do i.e. walking up hills
Chemotherapy patient, 9+ yrs

I have kept quite well since the treatment came to an end apart from the odd niggle. I have since had both hips replaced and am now suffering with anaemia
Alkylating Agents and Rituximab patient, 9+ yrs

Breakdown of the physical impact the 76 respondents have experienced post-treatment



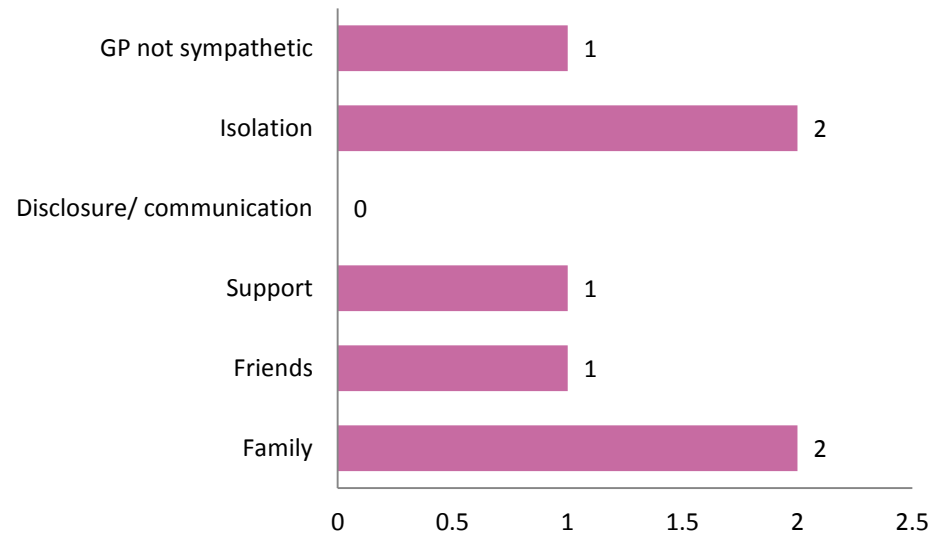
Insights

- The incidence of immune problems and infections was highest among respondents (49%) followed by fatigue and tiredness (47%)

General fatigue, less active with family and friends. I have to select specific events to do and then hope that I have the energy to do them
Alkylating Agents patient, 6-8 yrs

Relative isolation due to avoiding infection in crowds, difficulty in making medium term commitments due to unpredictability of health and less confidence in undertaking some activities
Rituximab and Bendamustine patient, 6-8 yrs

Breakdown of the relationship impact the 4 respondents have experienced post-treatment



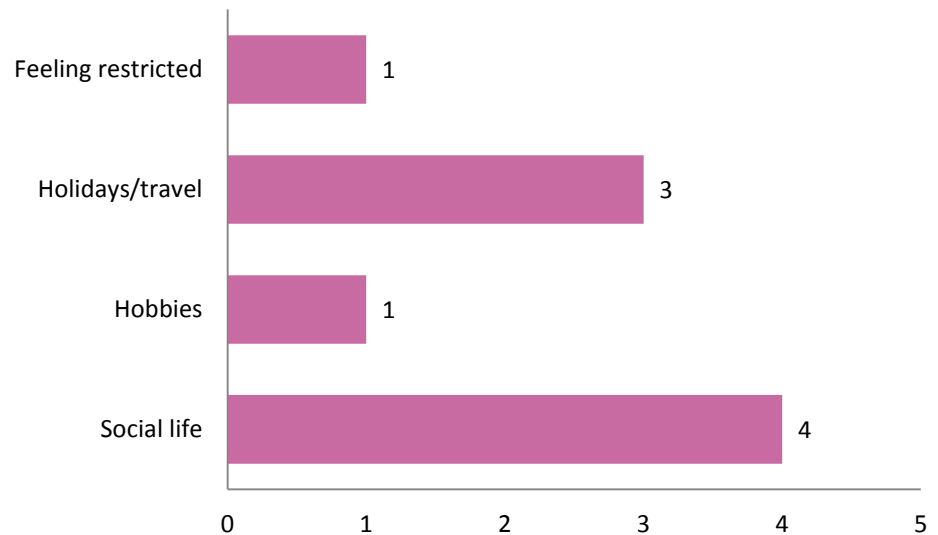
Insights

- The incidence of feelings of isolation and family relationships were highest among respondents (50%)

Adverse effect to treatment. Unable to travel abroad and book holidays in advance due to pending treatment and after effects
Alkylating Agents Rituximab and Bendamustine patient, 9+ yrs

Low platelet/neutrophil/Hb counts. Advised to eat cooked foods only and no eating out in restaurants, no social activities involving crowds, life is very restricted
R-CHOP, Rituximab and Bendamustine patient, 9+ yrs

Breakdown of the fun impact the 6 respondents have experienced post-treatment



Insights

- The incidence of impact on social life was highest among respondents (67%) followed by an impact on travel and holidays (50%)



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Conclusions and recommendations

- Overall, incidence of **physical QoL** issues were highest across both groups (72% watch and wait and 86% post-treatment)
 - This suggests that education on the disease progression of CLL should be of equal importance for both watch and wait and post-treatment patients
 - For **watch and wait** patients, education on symptom progression and monitoring will be important
 - For **post-treatment** patients, education on monitoring side effects will be important
 - Fatigue and tiredness was a particular issue for 77% of the watch and wait patients, suggesting it would be beneficial to ensure advice is available on how to manage this, as well as prioritising treatment innovation in this area
 - Infections and immune system issues increased after treatment, with 49% of post-treatment respondents reporting issues compared to 36% of the watch and wait patients. This suggests that greater research into treatments for those who have already incurred immune system problems is needed for CLL patients
 - Anecdotal responses suggest that watch and wait patients would benefit from practical guidance and advice about when to visit a doctor concerning an infection – as well as better GP education around CLL management

Conclusions and recommendations...cont'd

- Incidence of **emotional QoL** issues was high among the watch and wait group (85%) but dropped to 57% in the post-treatment group
 - This suggests that patients need much more emotional support to deal with living with CLL than those who have been on treatment. 85% of **watch and wait** respondents experienced feeling of anxiety and concern about living with CLL and more than a third of respondents experiencing the emotional impact of CLL expressed issues around disclosure and communication about their condition
- Incidence of **security, relationships** and **fun** QoL issues were low among both groups
 - This could be due to the survey design (which allowed free text responses only i.e. there were no pre-defined lists/triggers to consider issues in these areas). Security, relationships and fun could also be perceived to be 'secondary' QoL issues (with the physical or emotional issues being primary issues)

Insights

- Taken together, the incidence of QoL issues suggest that patients would benefit from being treated in a holistic manner, in which their care is managed by a multidisciplinary team. This would ensure that physical issues, such as infections and emotional issues, such as anxiety, were managed by the most suitable healthcare professional
- This would ensure that patients receive the best possible treatment, management and care for their health needs

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Future surveys

- It is recommended that future surveys should further explore the physical and emotional impact of living with CLL, particularly what support and advice people living with CLL have received. A good understanding of what support to offer patients and at what stage of the disease may help towards addressing the anxiety and concern watch and wait patients experience whilst living with CLL, as well as offering guidance and support to those who need practical advice on dealing with the side-effects of the disease or treatments currently available
- It would be valuable to further explore the impact on security, relationships and fun by including pre-defined lists in the survey
- It would be valuable to capture the age of respondents to explore any age related CLL issues
- The current survey does not take into account the type of support received from healthcare professional to combat QoL issues , therefore it would be valuable to capture this information in a future survey