

We are the only patient led UK charity supporting those affected by CLL and SLL and our purpose is to:

- **hold regular meetings with CLL consultants, researchers and other specialists**
- **provide up-to-date information on CLL and treatments**
- **provide an informative website: cllsupport.org.uk**
- **spread the word about CLL and its treatment**
- **support research into the treatment of CLL**
- **offer support and information about CLL and SLL**

Helpline: 0800 977 4396

Membership is FREE

Third National CLL Survey:

8 May – 29 July
2026

Second National CLL survey: March – April 2024
First National CLL Survey: May - June 2022

Why we conducted two surveys in 2026 – CLL Support's 22nd Anniversary year

CLL Support conducted the Third National CLL patient survey to:

- understand the current experiences and concerns of those with CLL and SLL
- share the findings and represent the views of the UK CLL and SLL community with the UK CLL Forum of specialists, researchers and scientists
- compare the results with those from previous surveys (2022 and 2024)

This year, we developed a second, bespoke survey to better understand the needs of members' partners, family, carers and friends

- The results show a distinct need for information relevant to their experiences

Methodology

As a patient-led charity, we invited: 1) UK patients with CLL or SLL and 2) their partners, family, carers and close friends to complete one of two anonymous surveys

Survey links were shared, with several follow up reminders, via:

- email invitations sent to members (>50% of responses)
- Website, social media and HeathUnlocked

We received a total **1,010 responses** across the two surveys:

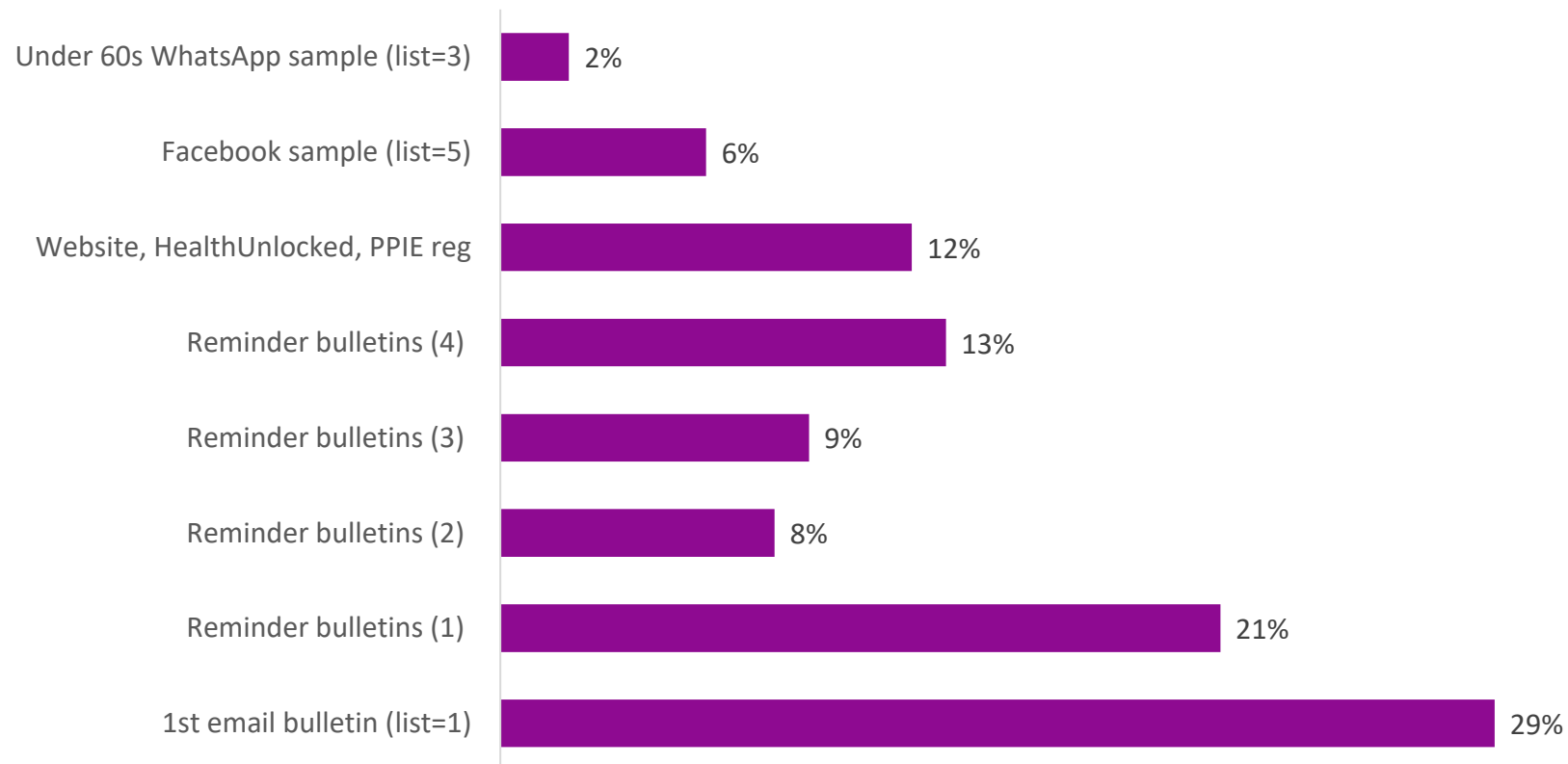
- **894** completed the patient survey
- **116** completed the partner/family survey

(Comparative sample sizes: n=1,010 in 2026; n=1,110 in 2024; n=702 in 2022)

Patient Sample

Respondents: 894 people with CLL/SLL completed the survey

Most respondents (633, 80%) completed the survey via direct member email, followed by the 'Website, HealthUnlocked, PPIE reg' (105, 12%) as the second most effective channels



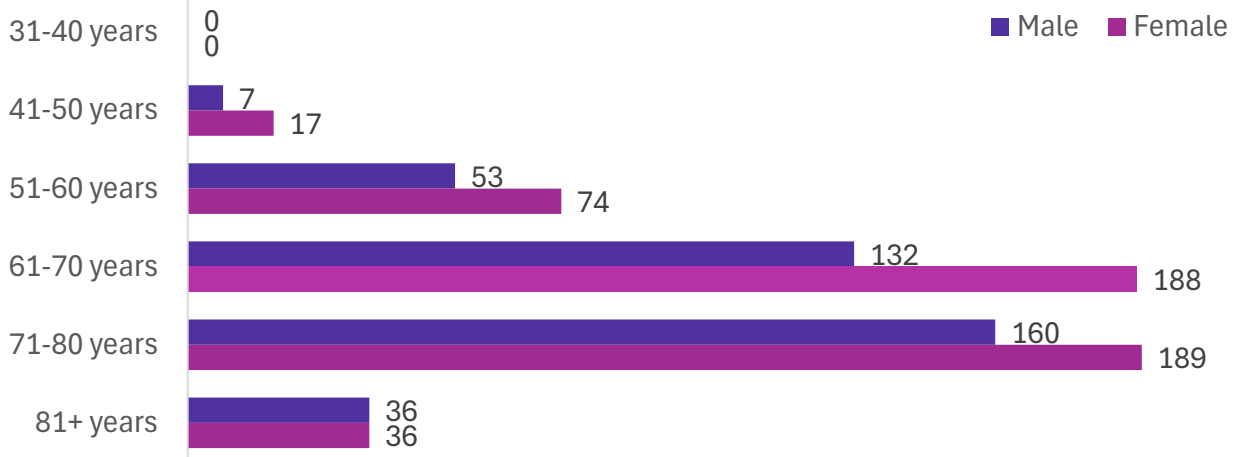
Patient sample characteristics (N=894)

2026 Survey respondents were predominantly CLL patients aged 61-80 years

Key takeaways

- 96% respondents were patients with CLL and 4% were patients with SLL
- All patients were aged 41+ years. Most representation was among patients aged 61-80 years
- As in previous years, the survey captured a higher proportion of female respondents (57%), reflecting CLL Support's predominantly female membership
- Given the higher incidence of CLL in men, this highlights a potential need for targeted outreach and support tailored to male patients
- SLL patients were more likely to have a recent diagnosis (61% in <5 years) compared to CLL patients (33% in <5 years)

Age and gender distribution



Diagnosis breakdown

858 (96%) Patients with CLL:

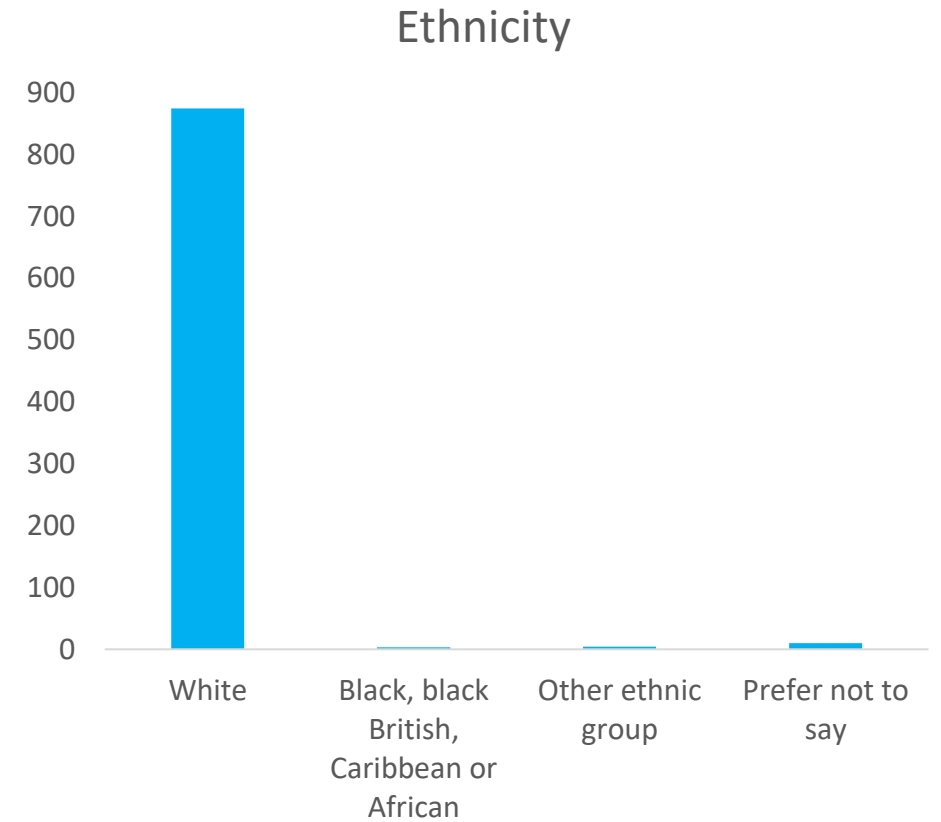
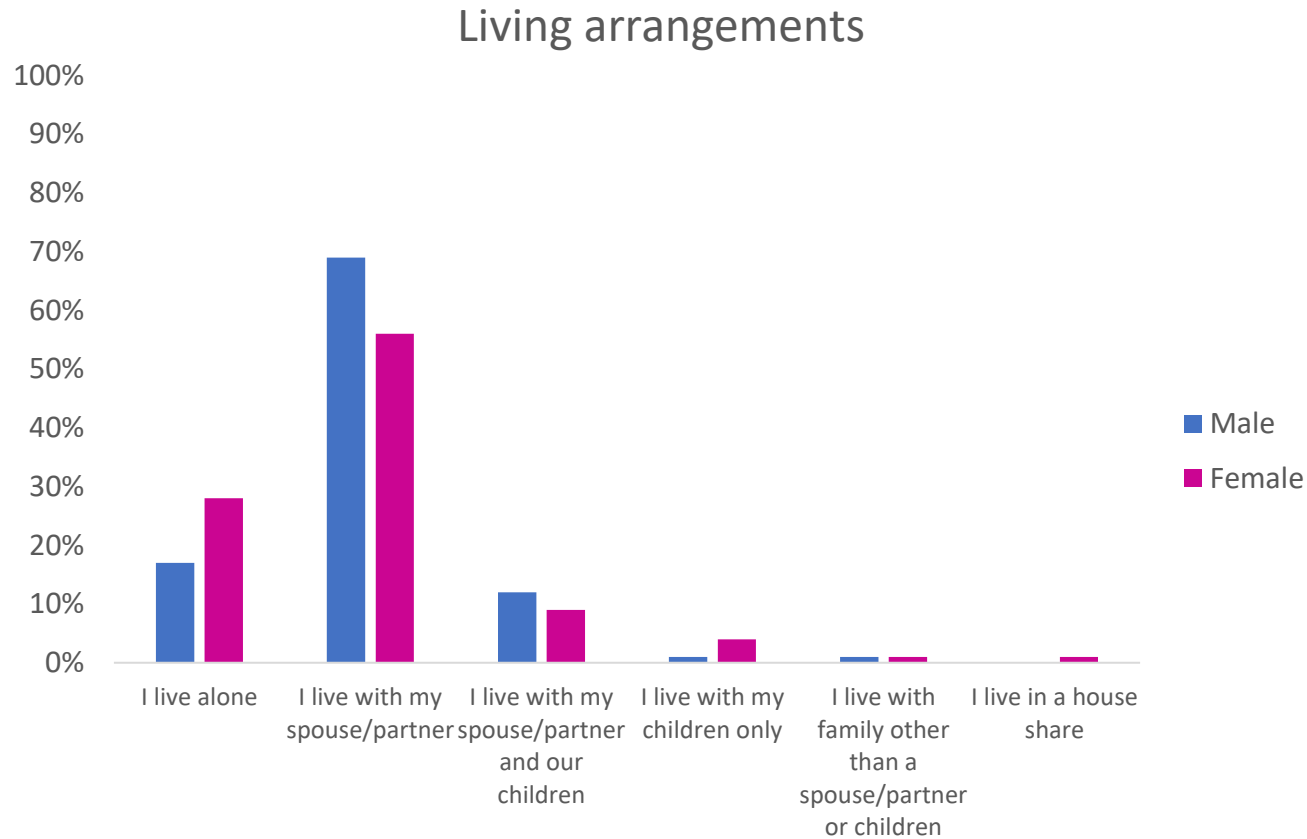
- Male: 378, Female: 479
- Time since diagnosis: <5 years: 284 (33%); 5-10 years: 275 (32%); 10+ years 280 (33%)

36 (4%) Patients with SLL:

- Male: 10, Female: 26
- Time since diagnosis: <5 years: 22^{*sig} (61%); 5-10 years: 9 (25%); 10+ years 5 (14%)

Patient sample characteristics – household makeup

- Most respondents live with their spouse/partner, with significantly more women living alone or with their children only, and significantly more men live with their spouse
- The vast majority of the sample were white British



In summary

Summary of 2026 learnings

- CLL is 96% of the total respondent population (97% in 2024 survey)
 - SLL has seen a 1% increase – too early and too small an increase to tell if efforts to engage a wider SLL membership are working, but the small increase is encouraging
- We recorded a high impact of SLL/CLL on quality of life
 - E.g. frequent current signs and symptoms, moderate physical and particularly, emotional impact
- CLL Treatment Guidelines were updated in 2025 so that the recently diagnosed should now be receiving more advice
 - It will be interesting to track this in those who have been recently diagnosed
- Important to pay attention to particular signs and symptoms
 - FATIGUE – this is still very high
 - PAIN – this is a previously unexplored side effect, but since it has been provided as an option, nearly a third say they experience it – we need to explore this
- Vaccinations – high engagement noted
- High satisfaction with CLL Support
 - Very consistent results with the past 2 years
 - More women access services, as in 2024
- Wearables: opinions are somewhat divided but overall respondents are favourable and open to using them to help manage CLL/SLL
 - People are interested even if they are not already engaged with these devices in other areas of their life

Mixed experiences with CLL/SLL

CLL is a very individual experience and I remember at diagnosis I did not understand this, that CLL is genetically diverse. Everything I read about CLL I thought applied to me and it took a long time to understand the wide variation.

CLL is such a weird disease, to be able to walk into a conference room full of people who "get it" was a huge relief, along with all the practical info on treatments before I started chemo.

There is very little understanding of CLL by the public and many doctors. Most people can't understand why it bothers you if you've had it for many years. I feel as though I have to be my own doctor all the time.

In hindsight when first diagnosed, I didn't ask enough questions

Distinct lack of knowledge being passed to patients. On diagnosis to be handed [only] a booklet was diabolical.

What helped me most was referral to a holistic appointment after 18 months of anxiety. I was then referred on to activities designed to help cancer patients. Every CLL patient needs this!

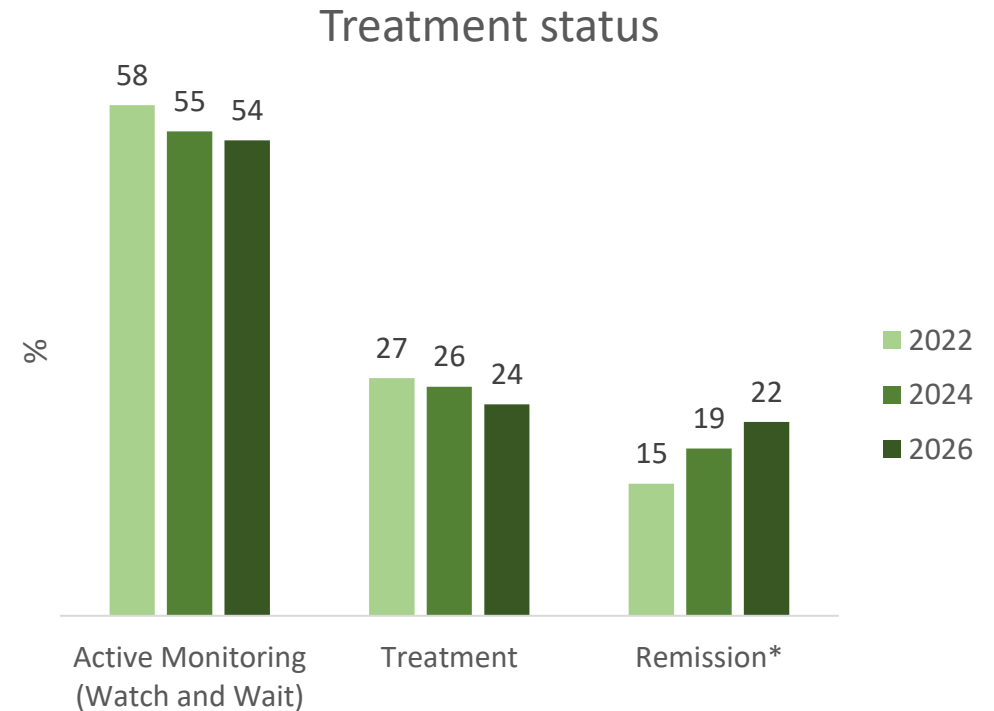
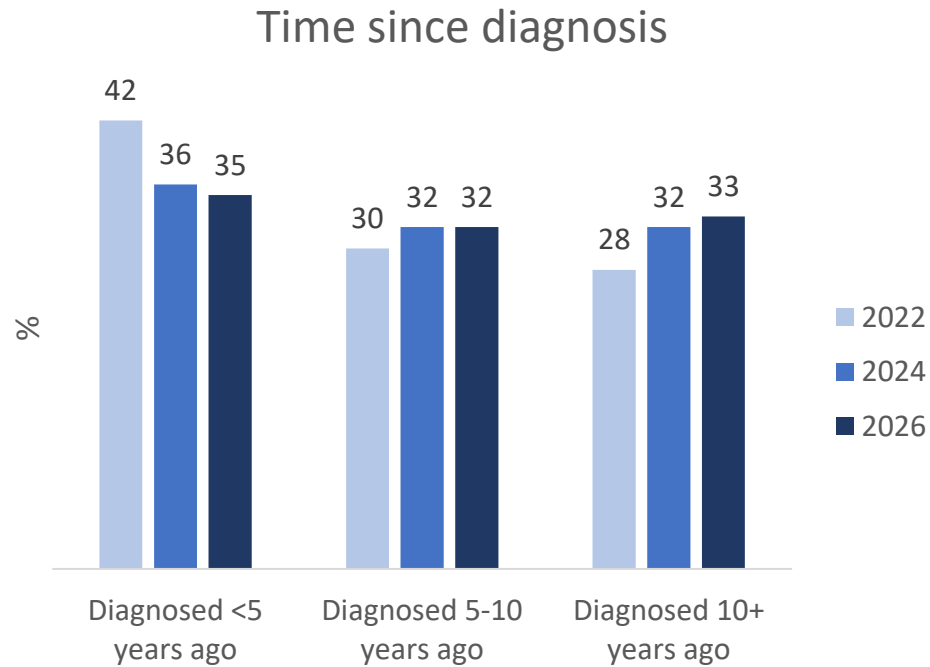
Survey results

Interpreting the results:

- Score /10 where 10/10 is the highest rating and 1/10 is lowest rating for each parameter

Time since diagnosis & treatment: 2026 vs 2024 vs 2022

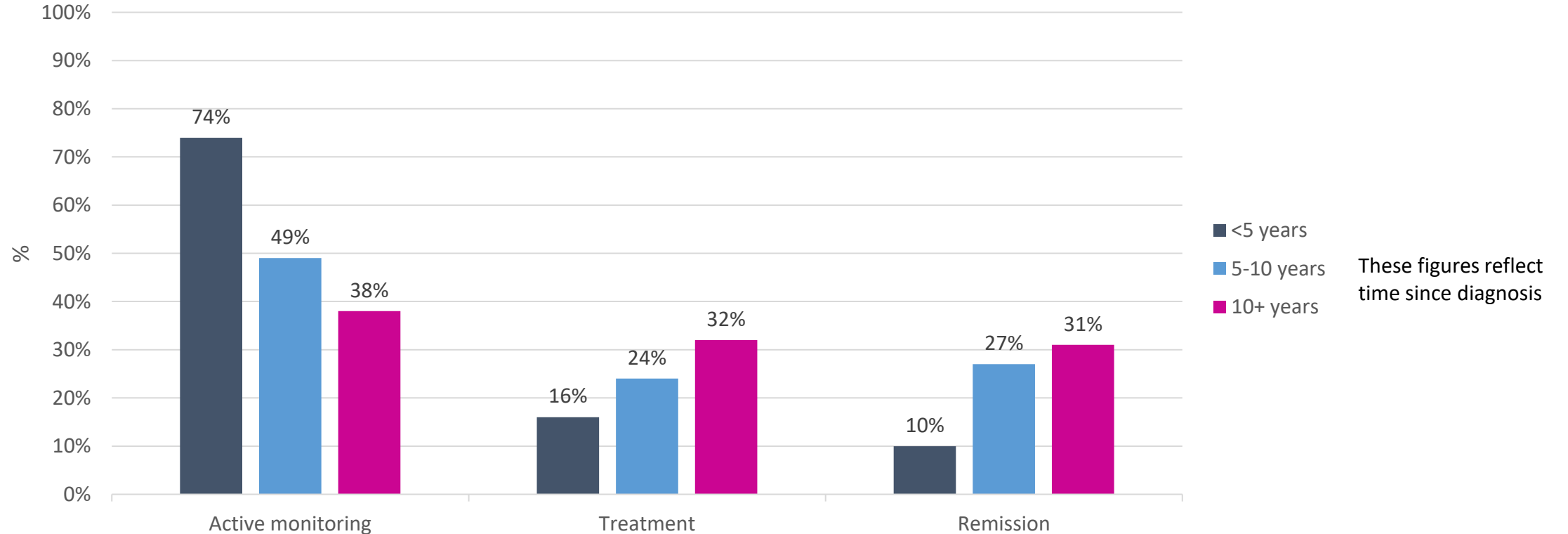
- Time since diagnosis was evenly distributed across all three timeframes
- More than half of the respondents (54%) remain on Active Monitoring, while the proportion in Remission (defined as 'back to active monitoring after treatment') has grown steadily over the past 4 years from 15% in 2022 to 22% in 2026.



*Remission was defined as 'back to active monitoring after treatment'

Current situation

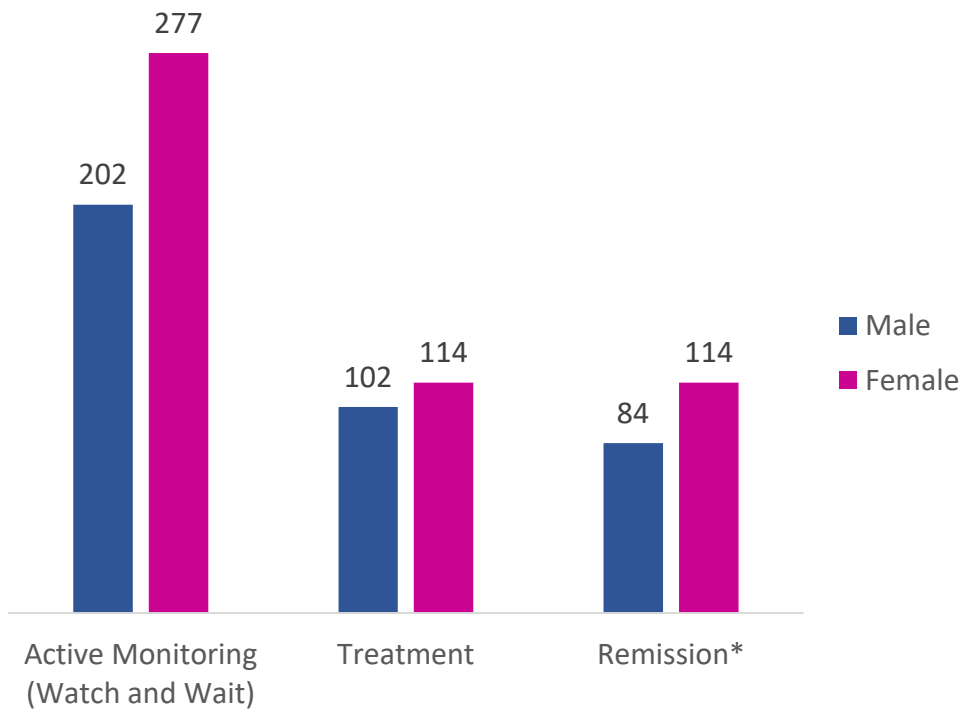
Most respondents were on 'active monitoring', particularly those more recently diagnosed. Of those on treatment, fewest were in the most recently diagnosed group, and more respondents diagnosed over 5 years ago, were in remission.



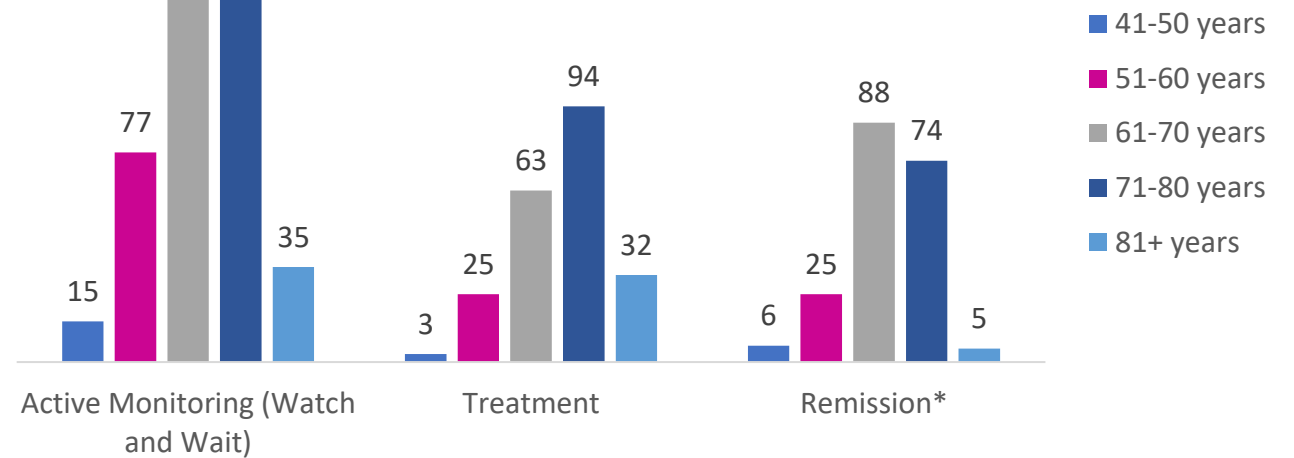
Treatment status by gender and age: 2026 Survey

Treatment status followed a consistent distribution across gender and age groups. Active Monitoring remained the predominant treatment stage across genders and age groups.

Treatment status by Gender



Treatment status by Age

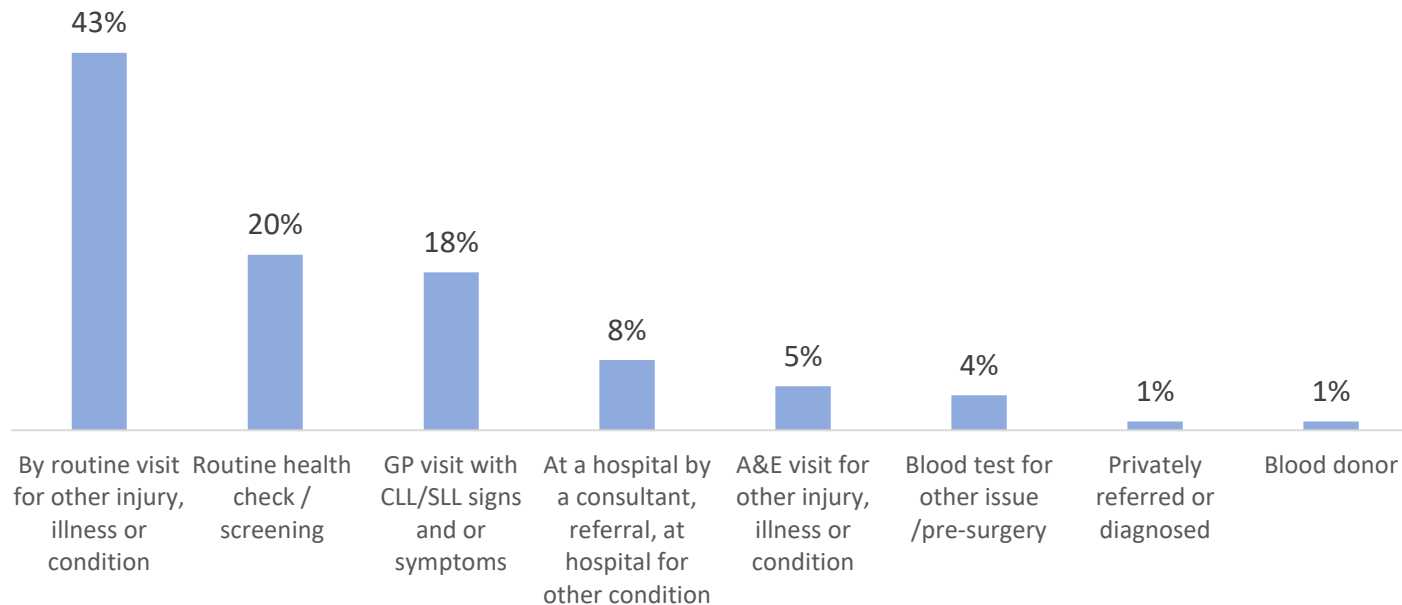


*Remission was defined as 'back to active monitoring after treatment'

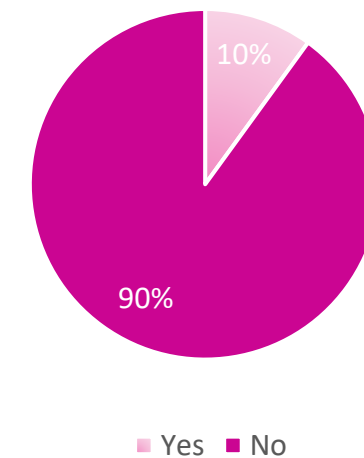
Route to diagnosis and family history: 2026 Survey

Most respondents were diagnosed incidentally during routine visits for other injury, illness or conditions. Only a minority presented directly with signs or symptoms of CLL/SLL. 10% reported a family history of CLL/SLL.

Route to diagnosis

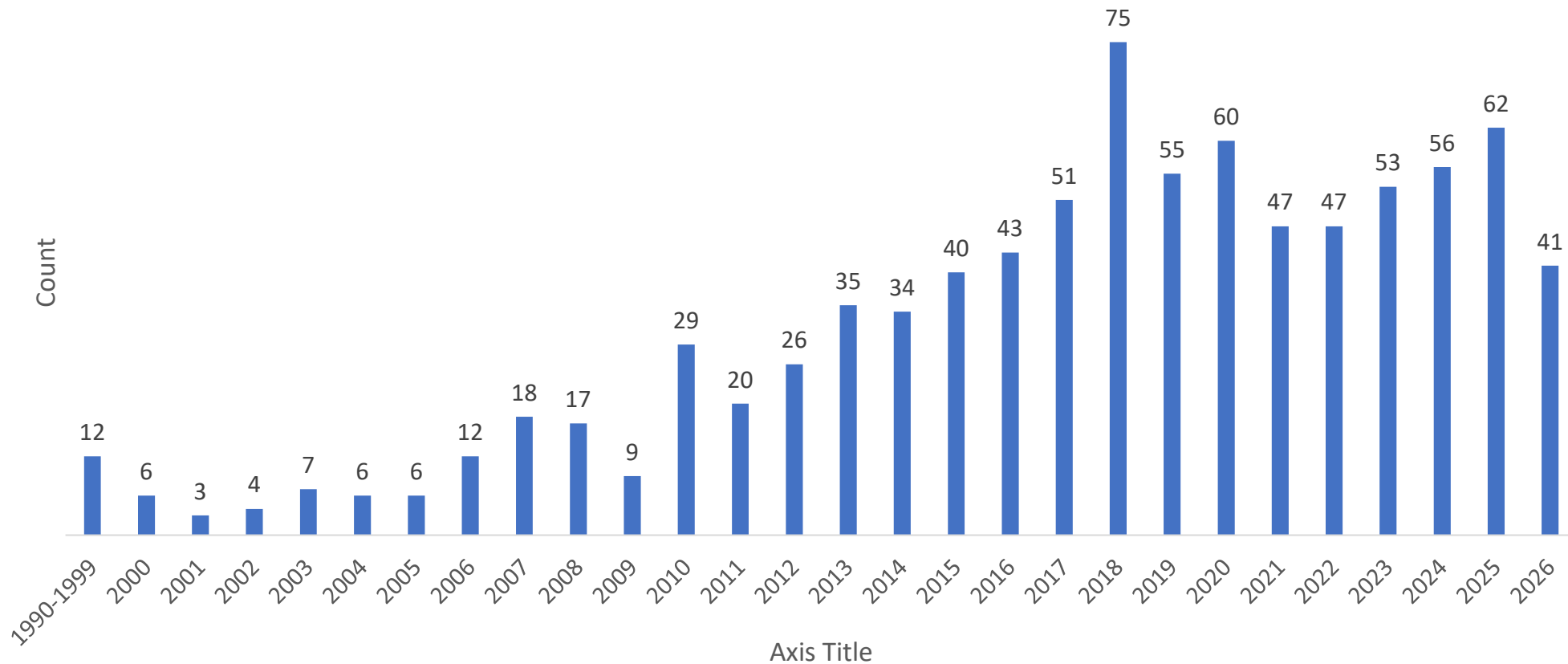


Family members also diagnosed with CLL/ SLL



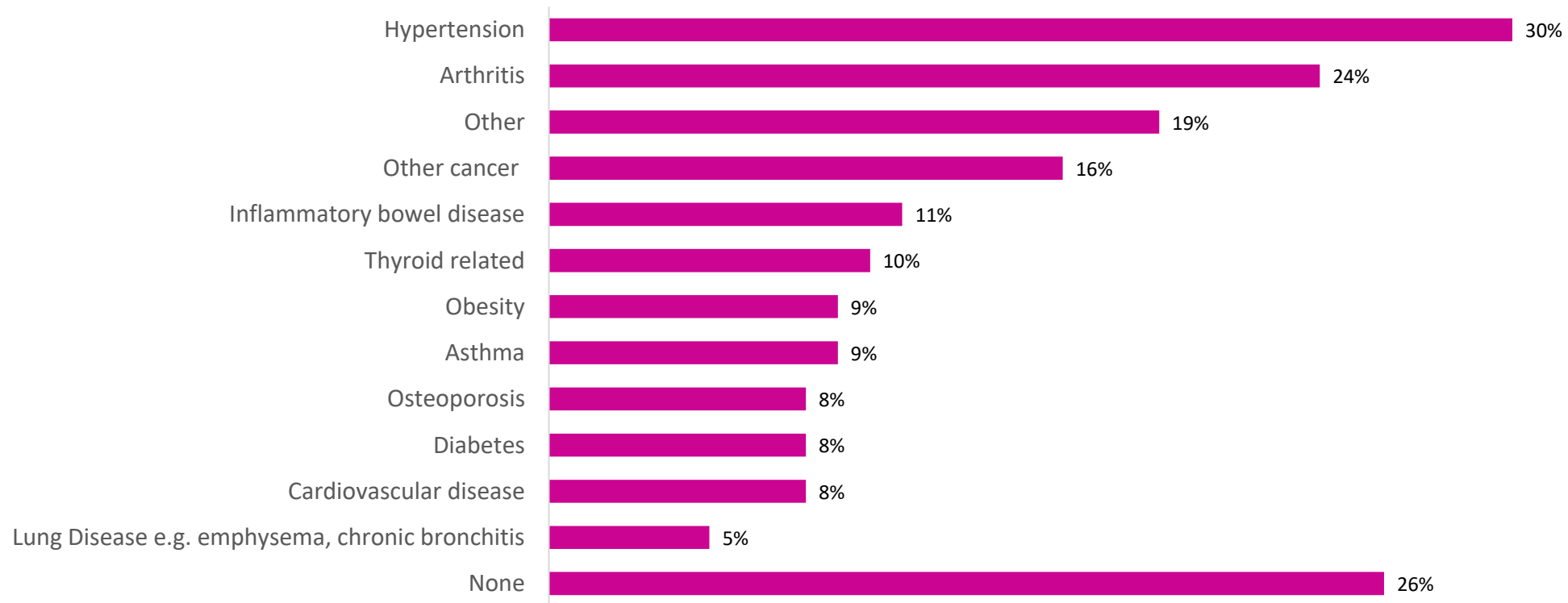
Year of diagnosis: 2026 Survey

Most respondents had been diagnosed in the last decade, peaking in 2018. Representation extends over 36 years (dating back to 1990), reflecting long-term survivorship in the patient community



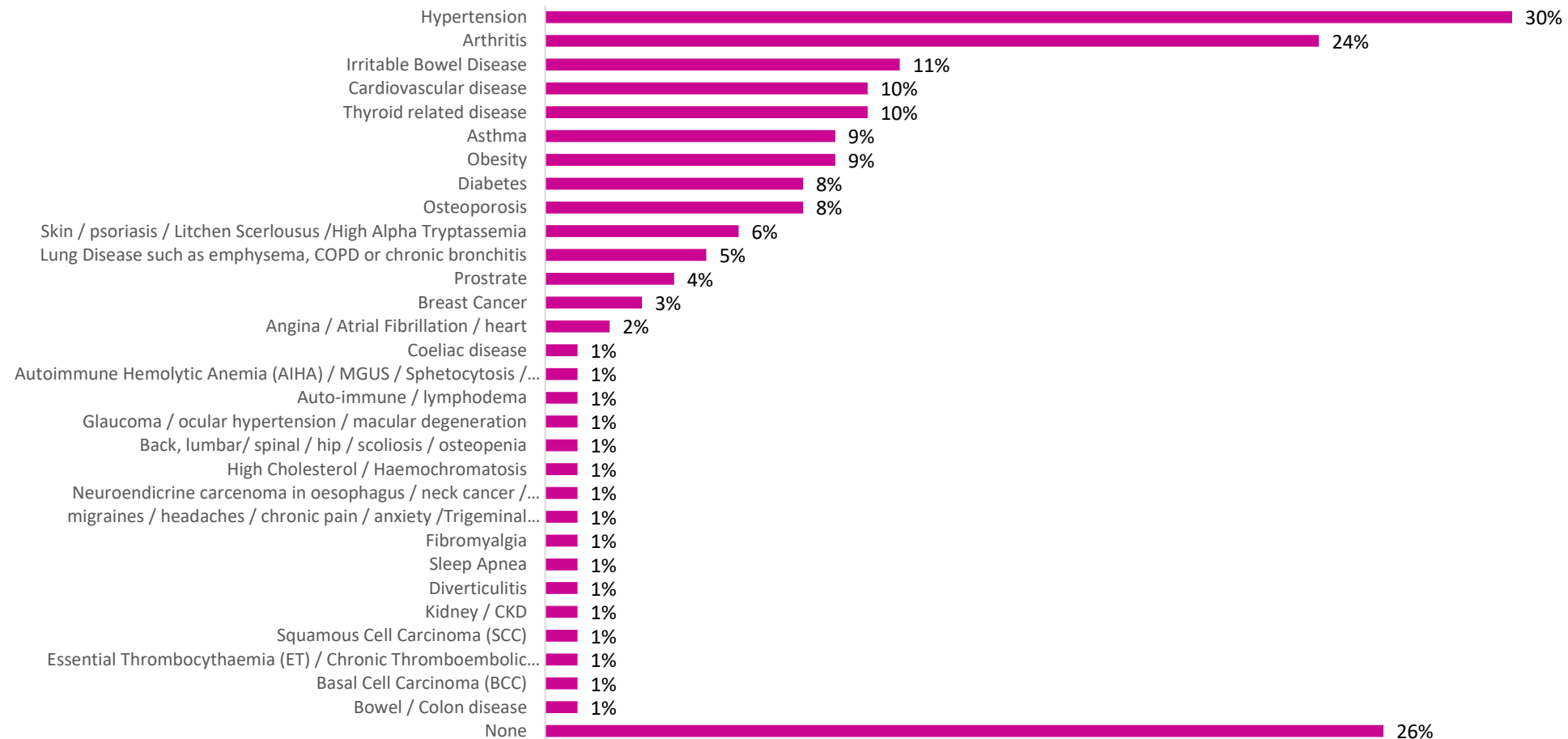
Patient comorbidities: 2026 Survey

Hypertension (n=268, 30%) and arthritis (n=218, 24%) were the most reported comorbidities in 2026, while 228 respondents (26%) reported having no comorbidities.



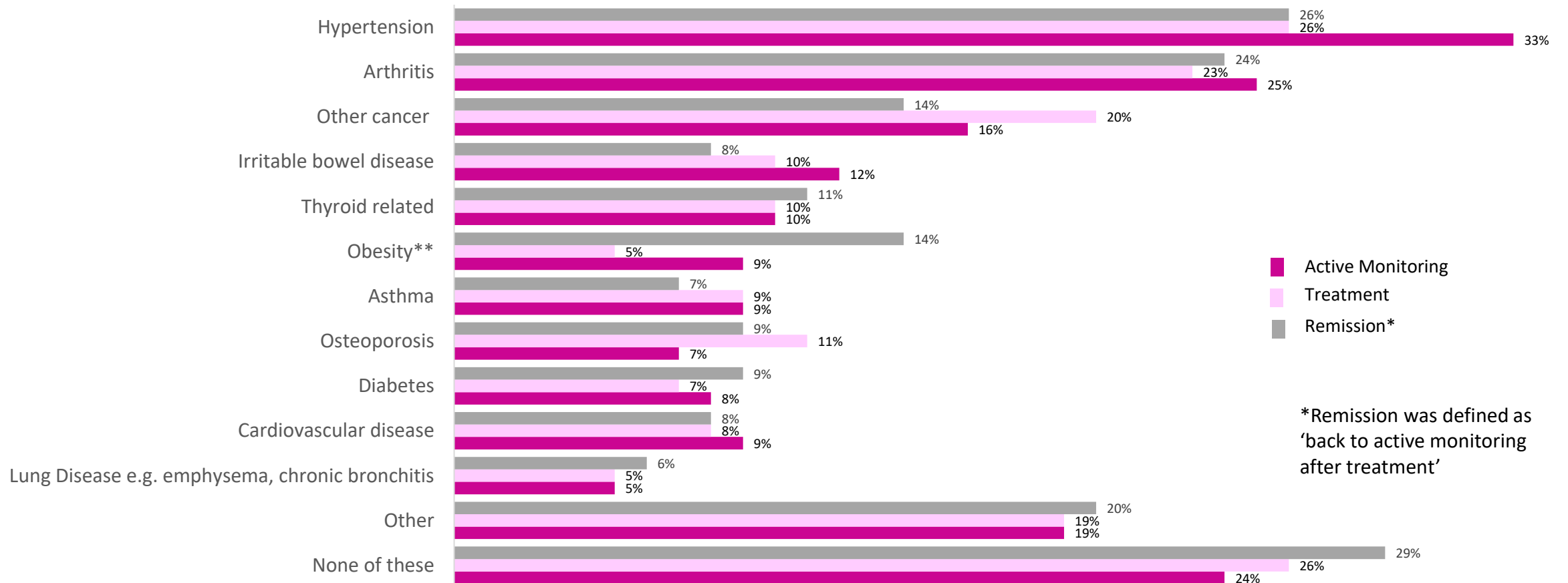
Patient comorbidities: 2026 Survey

Respondents reported numerous and varied comorbidities overall. Hypertension (n=268, 30%) and arthritis (n=218, 24%) were the most reported comorbidities in 2026, while 228 respondents (26%) reported having no comorbidities.



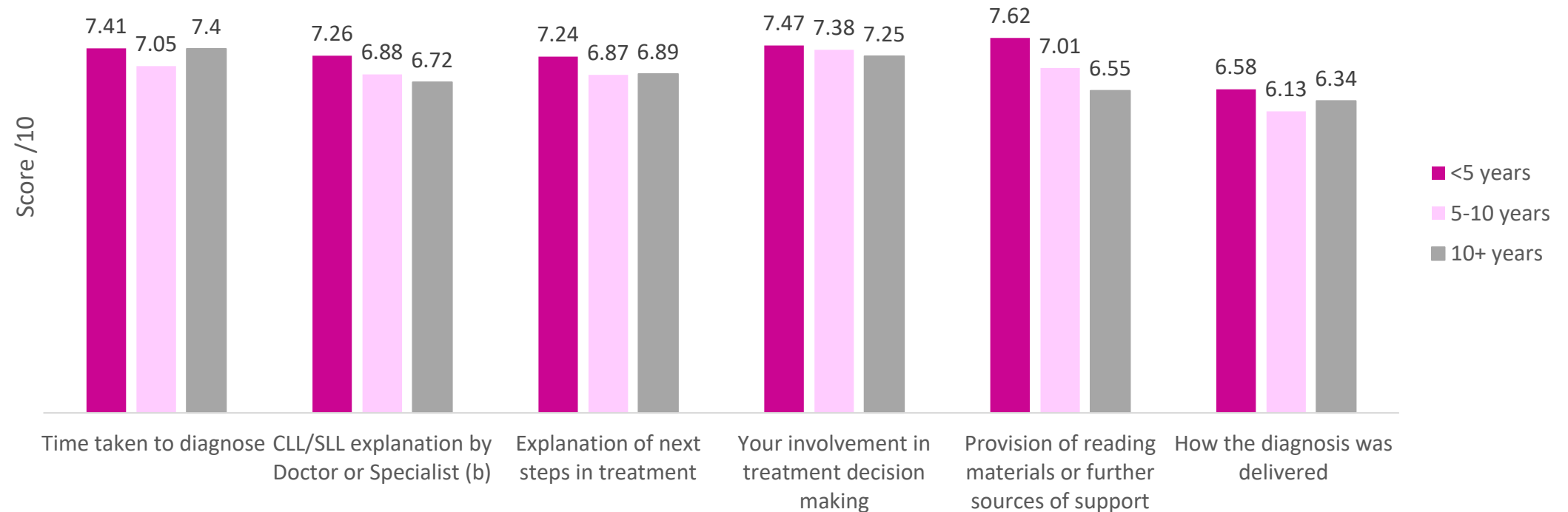
Comorbidities by treatment status: 2026 Survey

The proportion of patients reporting comorbidities and no comorbidities ('none of these') was similar by treatment status. Obesity was the only comorbidity to differ significantly between groups ($p < 0.05$) (9% Active Monitoring, 5% on Treatment and 14% Remission*)



Satisfaction at diagnosis by time since diagnosis: 2026 Survey

Relatively high satisfaction reported across all aspects of diagnosis. Patients diagnosed most recently (<5 years ago) reported higher satisfaction regarding explanations received and the provision of reading materials or support



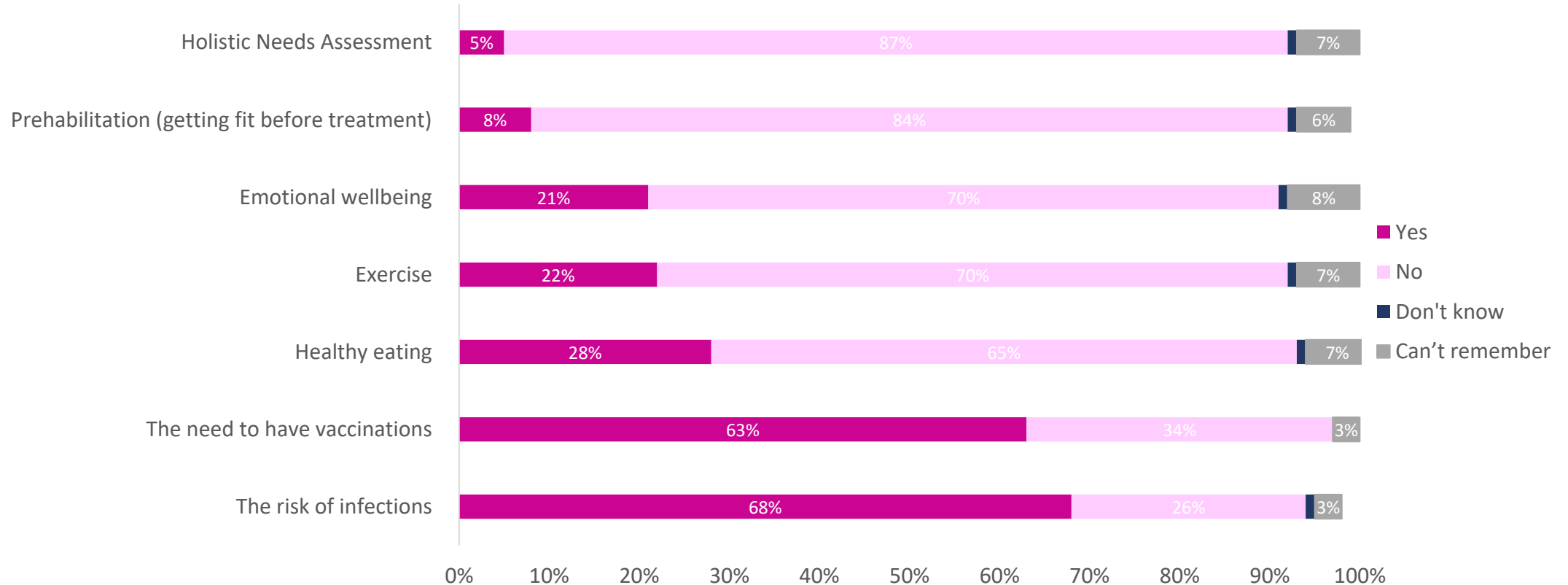
Q2. What year were you diagnosed with CLL/SLL? [Base n=894]

Q5. From your general experience, how satisfied were you with the following aspects of CLL/SLL [Base n=894]

Topics discussed at diagnosis: 2026 Survey

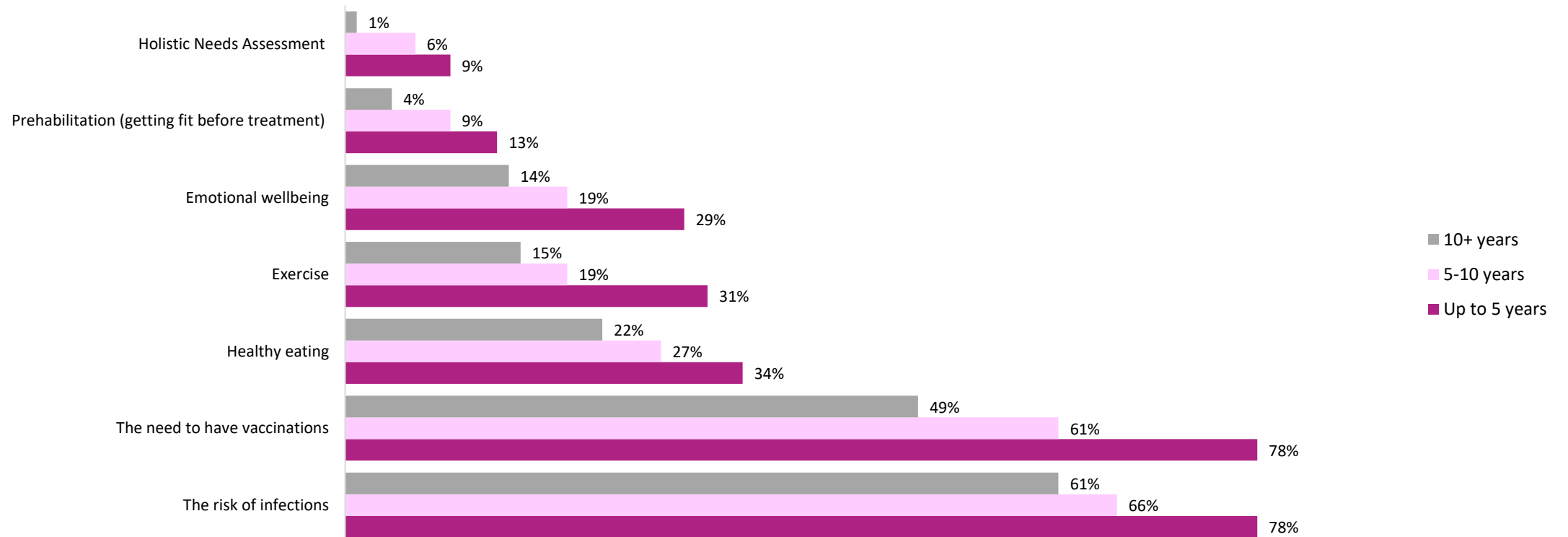
Infection risk (68%) and vaccination needs (63%) were the most frequently discussed topics at diagnosis, covered in approximately 2 out of 3 patients. Holistic needs (5%) and prehabilitation (8%) were rarely addressed.

Now these are included in the 2025 guidelines, we hope to track an increase in discussion at diagnosis over time



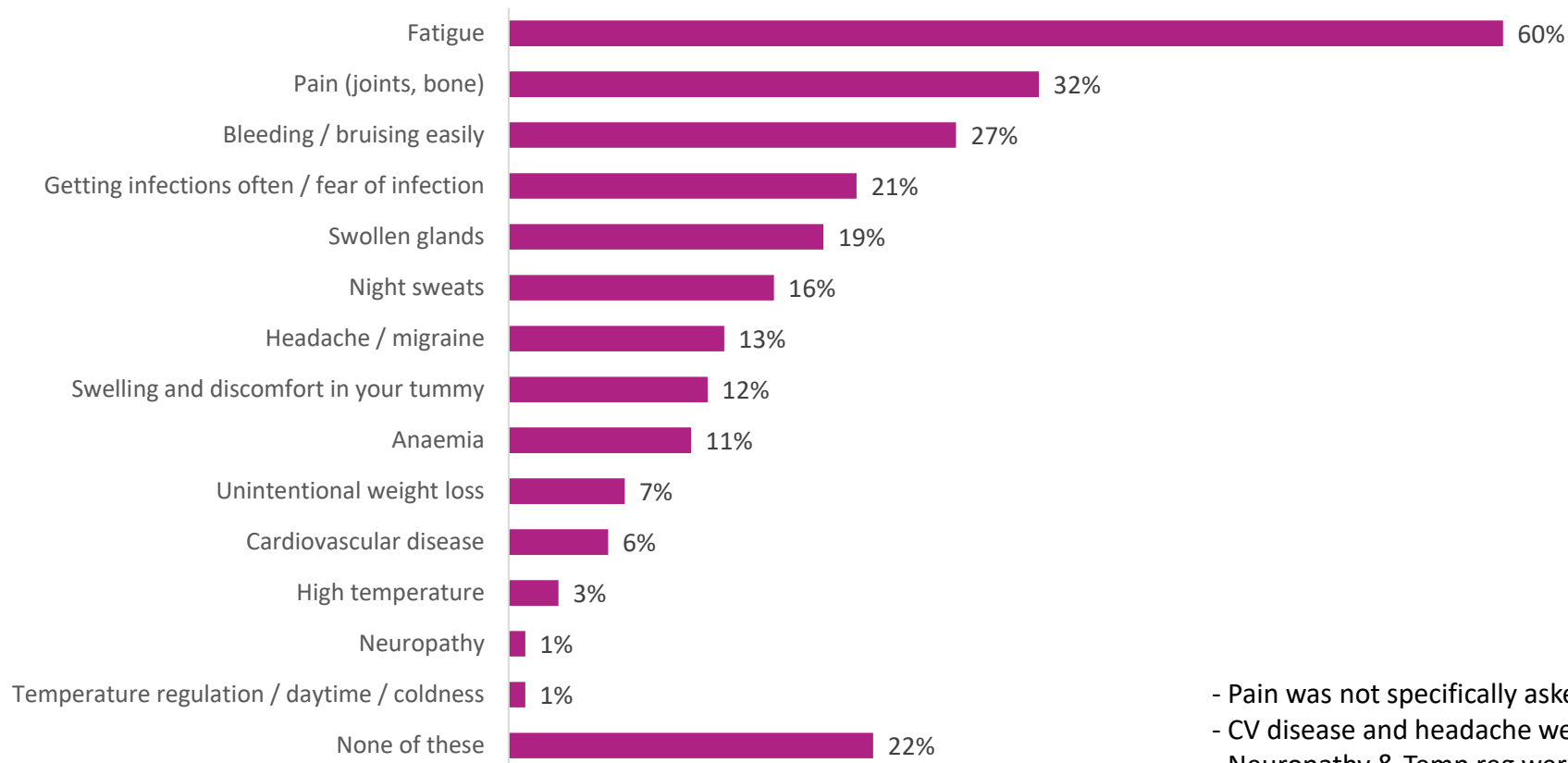
Topics discussed at diagnosis by time since diagnosis: 2026 Survey

All the specified topics were more likely to be discussed with patients diagnosed in the past 5 years, when compared to those diagnosed more than 10 years ago ($p < 0.05$)



Current signs and symptoms: 2026 Survey

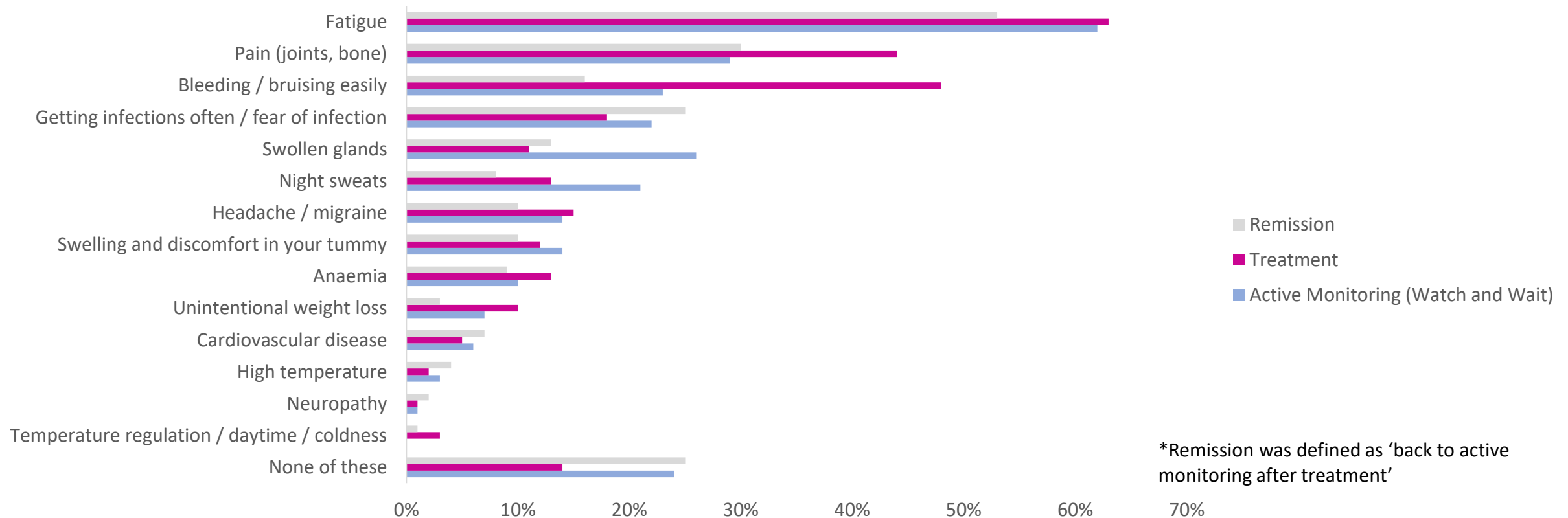
Fatigue remains the primary symptom reported by patients (542 respondents, 60%) followed by joint/bone pain (282 respondents, 32%) and bruising/bleeding easily (241 respondents, 27%). More than a fifth of respondents reported being symptom free ('None of these').



- Pain was not specifically asked about in 2024 (it came under 'other')
- CV disease and headache were also not asked in 2024
- Neuropathy & Temp reg were coded under 'other' 2026
- All other parameters under 'other' were <1%

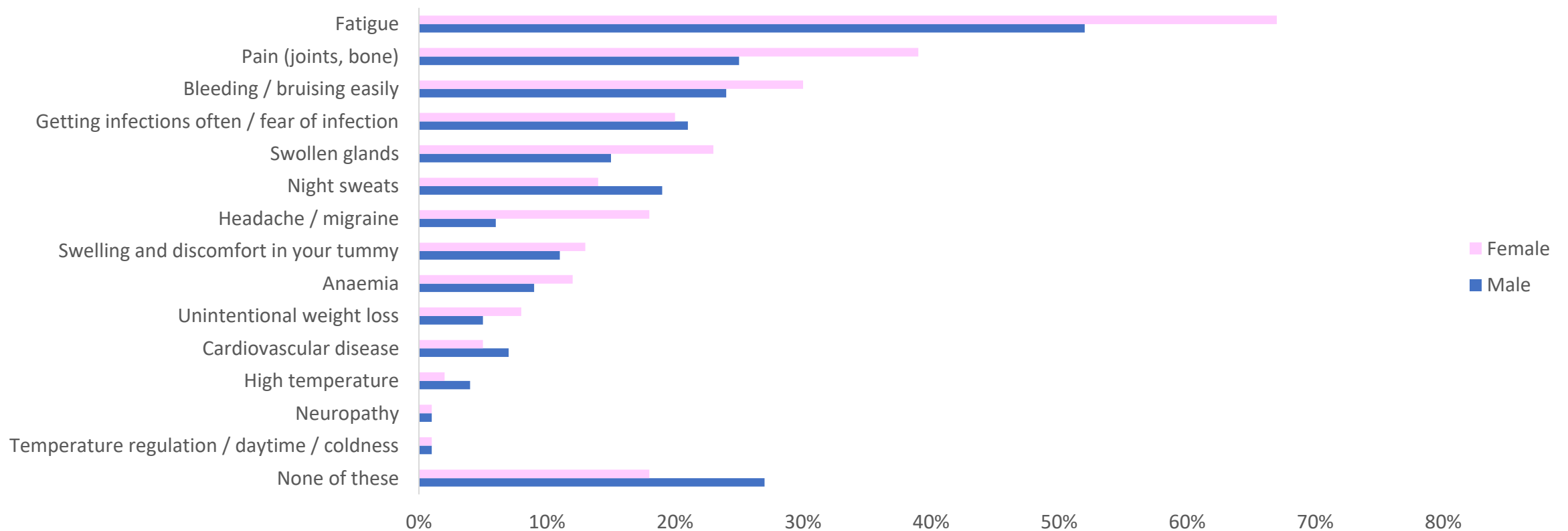
Current signs and symptoms by stage: 2026 Survey

Most participants experienced signs and symptoms of disease or treatment. Those in treatment were more likely to be experiencing fatigue, bleeding/bruising easily, unintentional weight loss, pain, muscle ache. Those in active monitoring were more likely to experience fatigue, night sweats, swollen glands.



Current signs and symptoms by gender: 2026 Survey

Women experienced the following significantly more often: fatigue, bleeding/bruising, swollen glands, headache and pain; men were more likely to report no signs or symptoms



Fatigue can be debilitating...

Fatigue, fatigue, fatigue. This was how my CLL was discovered 11 years ago and this has never been addressed only dismissed because my bloods showed my CLL was not “bad enough” for fatigue.

Fatigue is most debilitating aspect for me and I don't feel it is taken seriously - dismissed as not being due to CLL but more often than not referred to as CFS. Never suffered with fatigue in my life before!!!

Managing fatigue is difficult. I know I don't take enough exercise but very difficult to exercise when fatigued so I have enlisted in an online physio routine that is little and often 15 minutes a day building both strength and mobility for the over 60s. This helps me to feel I am doing 'something' to break the fatigue/weakness cycle.

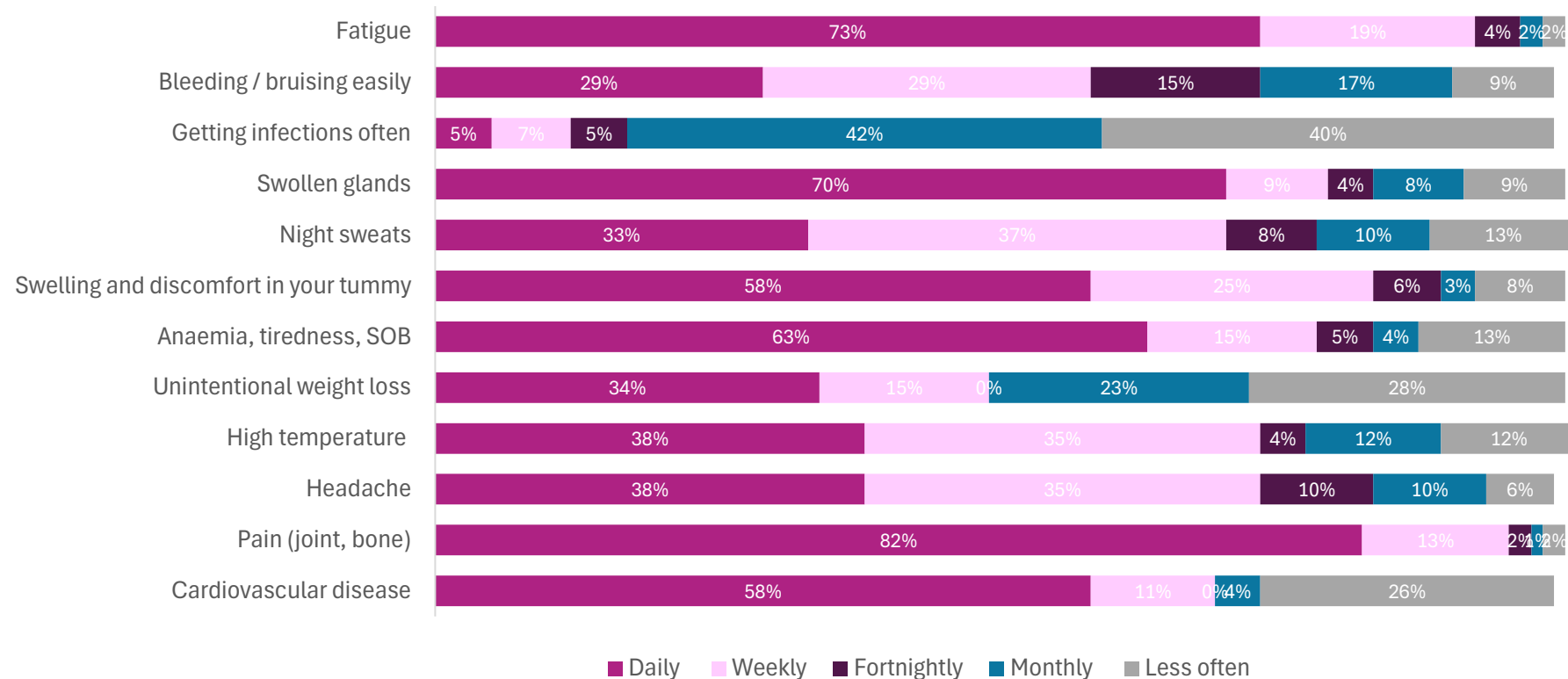
Fatigue (for me) is really bad, but get dismissed by my consultant and GP does very little

I feel that the fatigue is something the Consultants and GP just expect you to get on with.

The chronic fatigue is debilitating, and family and friends don't realise how badly it affects CLL sufferers. At times I find my daily routine hard to sustain and I just want to sleep.

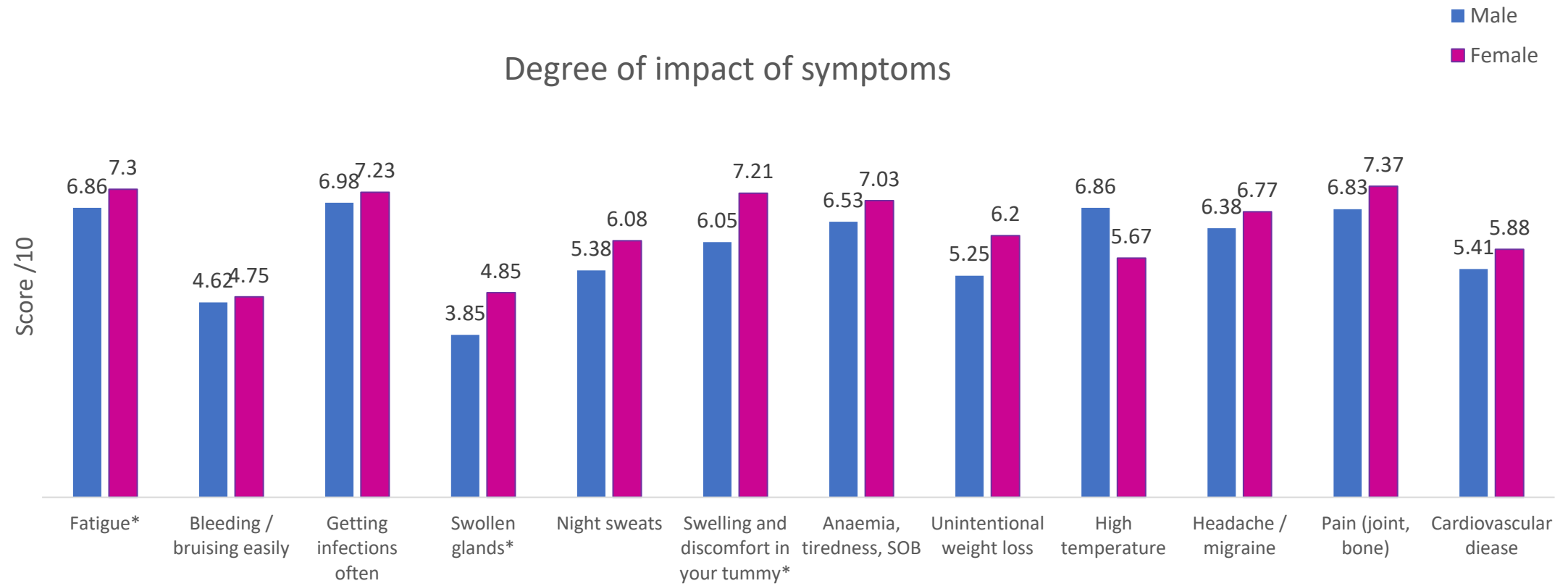
Frequency of experiencing symptoms: 2026 Survey

Fatigue, swollen glands, swelling/discomfort, anaemia, tiredness and shortness of breath (SOB), pain and cardiovascular disease were experienced daily by more than 50% of those who experienced the symptom



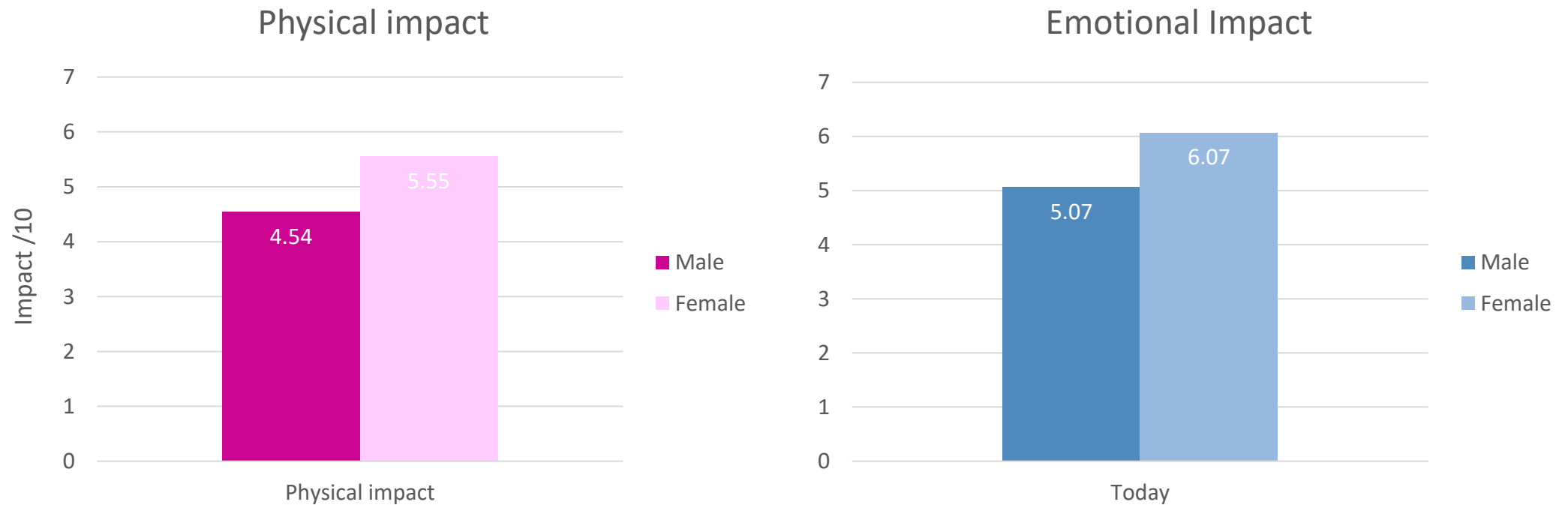
Impact of symptoms

In general women rated their symptoms as having more of an impact on their daily lives – night sweats, swollen glands, and swelling / discomfort in tummy, were rated as being significantly more impactful



Impact on quality of life across gender

Women rate both the physical impact of CLL / SLL to be significantly greater than men do, and the emotional impact to be directionally greater (not significant)



Q8a. How much has your diagnosis of CLL/SLL affected your quality of life from a physical perspective? [Base n=984] – Score/10

Q8b. How much has your diagnosis of CLL/SLL affected your quality of life from an emotional perspective? [Base n=894] – Score /10

The emotional impact can be great

Living with CLL is difficult whether being treated or not. Even when treatments work there is still the underlying existential threat that takes an enormous toll on the psyche. Anxiety has been the worst aspect of CLL.

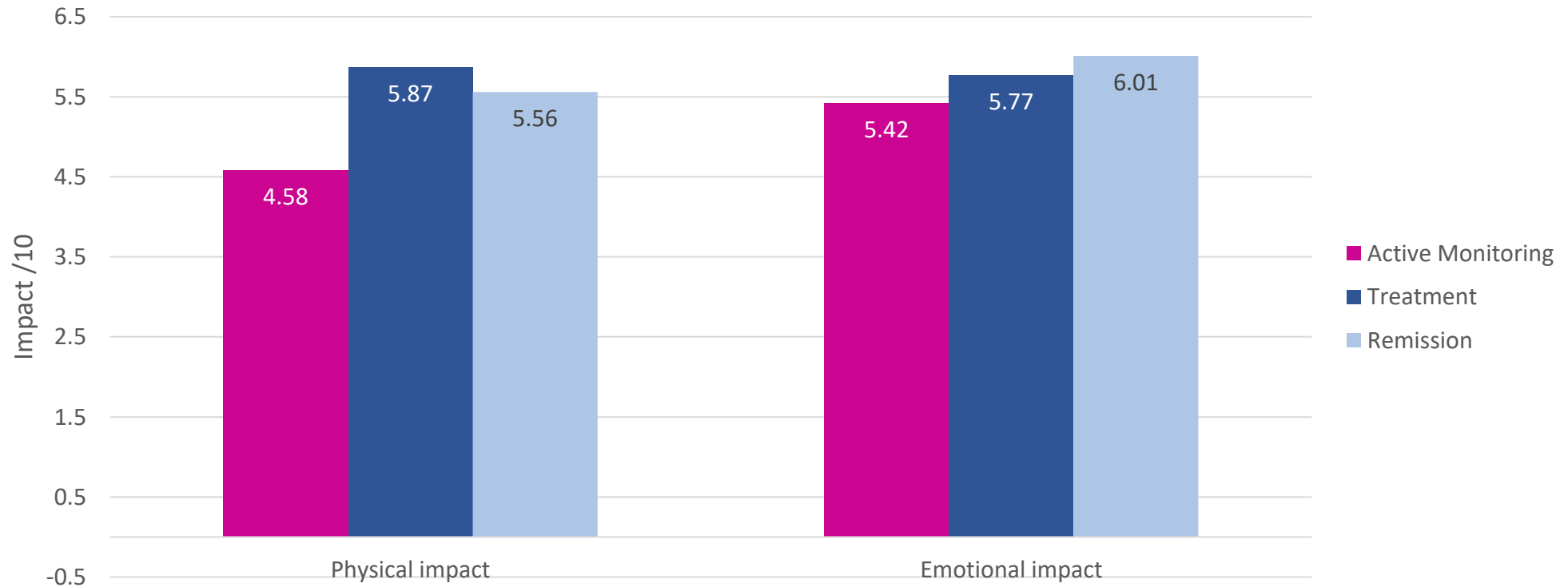
CLL diagnosis brings with it mental health issues , feeling insecure and vulnerable

Watch and wait is nerve wracking and they may miss something serious due to other conditions

The mental side of CLL is the hardest to deal with, the not knowing what the future has to hold

Impact on quality of life today across current situation

Respondents on active monitoring, rate the lowest impact on their quality of life



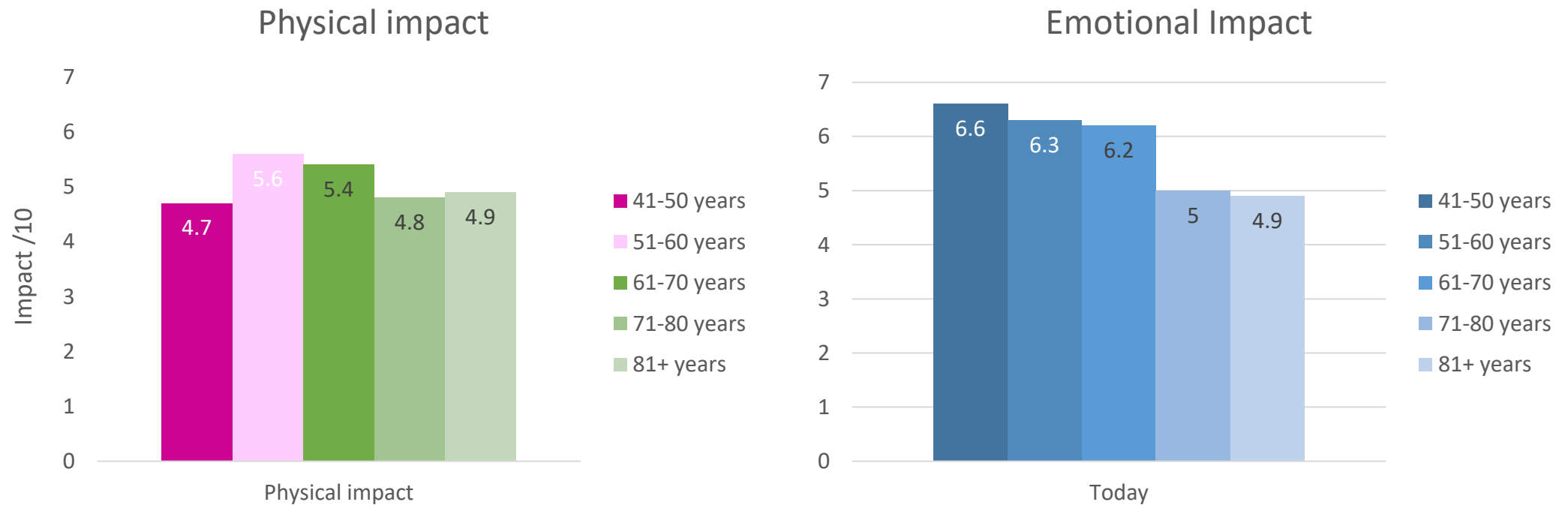
Q8a. How much has your diagnosis of CLL/SLL affected your quality of life from a physical perspective? [Base n=894] – Score /10

Q8b. How much has your diagnosis of CLL/SLL affected your quality of life from an emotional perspective? [Base n=894] – Score /10

Impact on quality of life across age

Physical impact: those aged 51-60 & 61-70 years each have significantly greater impact than the 71-80 ages group

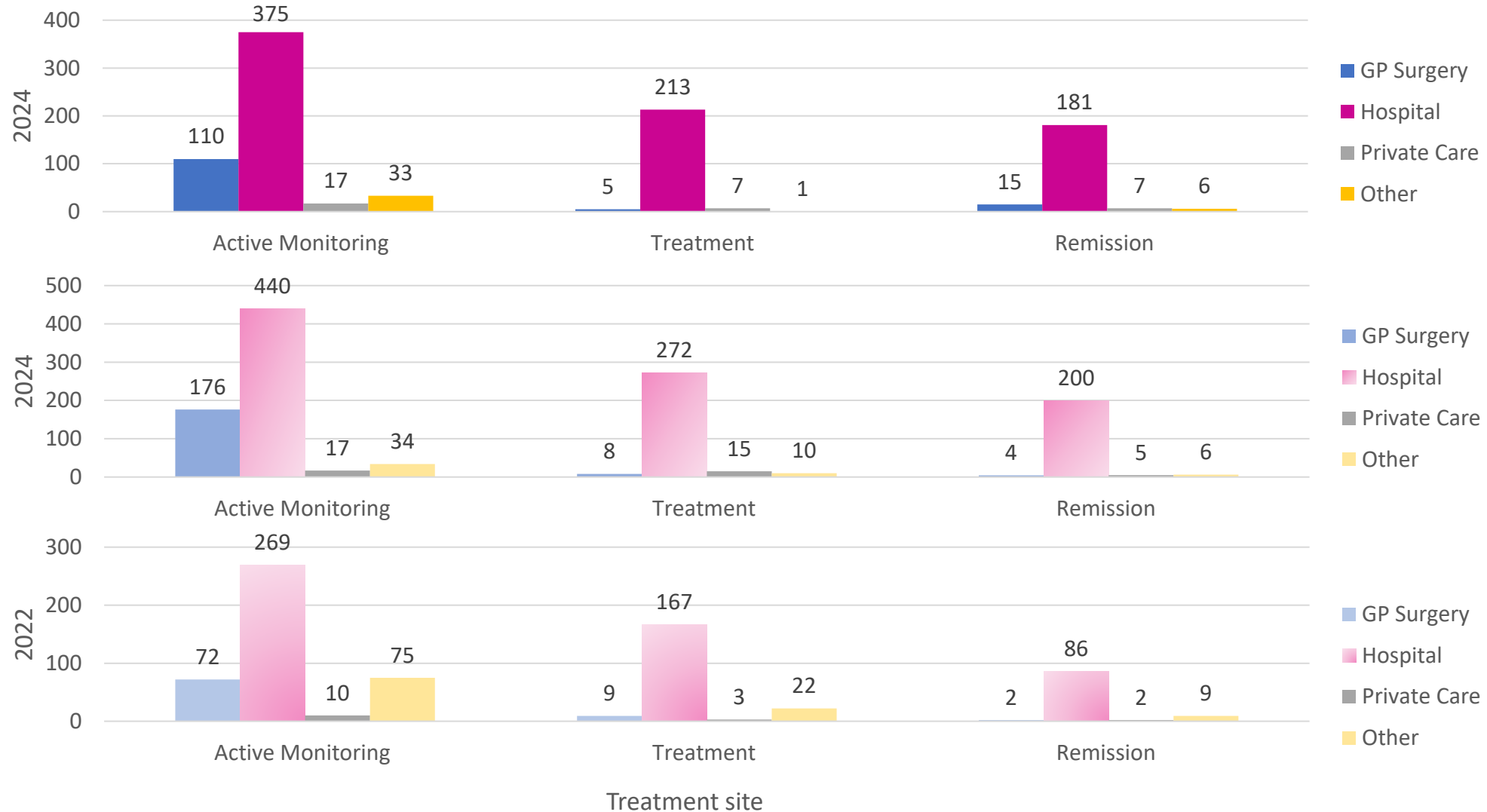
Emotional: those aged 41-50, 51-60 & 61-70 years are significantly more emotionally impacted than the 71-80 & 81+ year age groups



Q8a. How much has your diagnosis of CLL/SLL affected your quality of life from a physical perspective? [Base n=984] – Score/10

Q8b. How much has your diagnosis of CLL/SLL affected your quality of life from an emotional perspective? [Base n=894] – Score /10

Sites of treatment

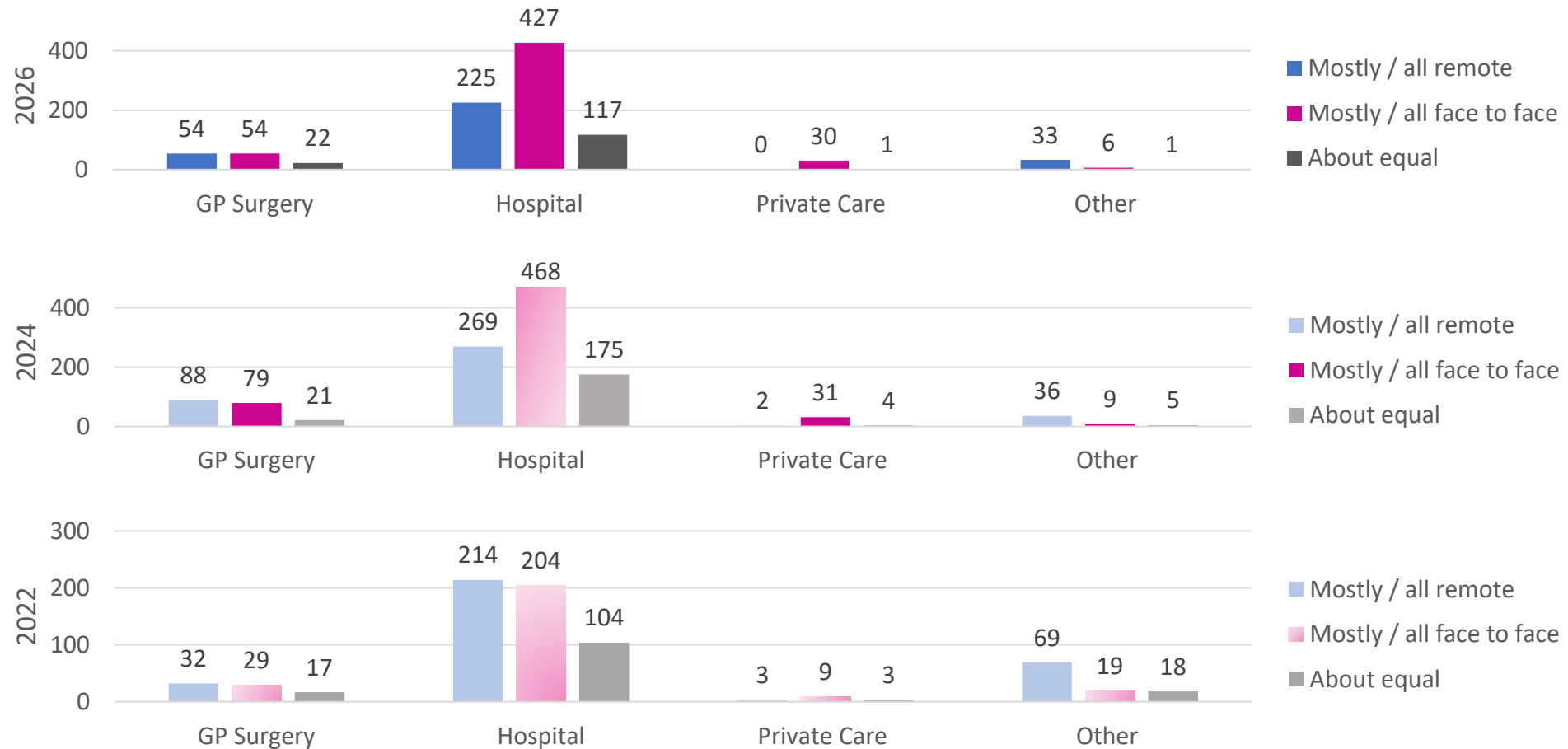


Q6. What is your / their current situation? [Base n=894][Base n=1110][Base n=702]

Q9a. Where do you currently receive therapy for CLL/SLL? Select all that apply. [Base 894][Base n=1110][Base n=702]

Consultations continue to be predominantly face to face

Consultation format

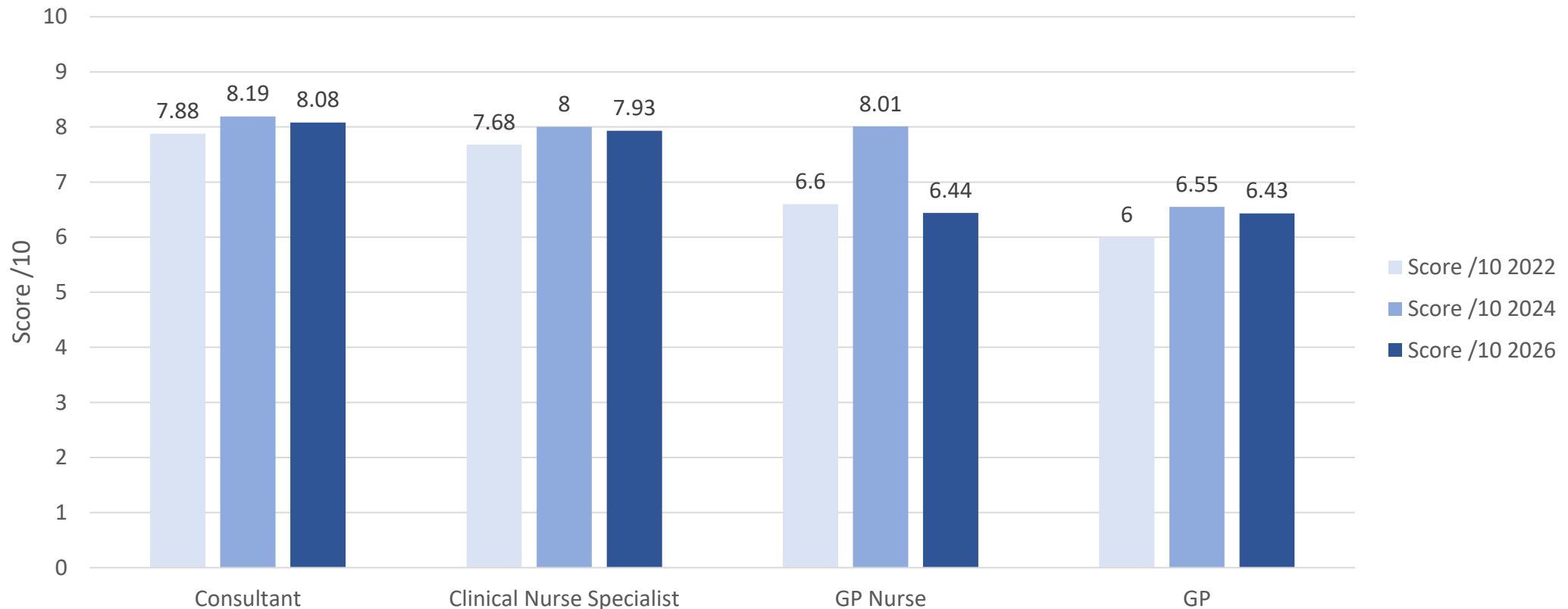


Q9a. Where do you / they currently receive therapy for CLL/SLL? Select all that apply. [Base ALL n=894][Base n=1110][n=702]

Q9b. And how do you / they currently receive therapy for CLL/SLL? [Base n=894][Base n=1110][Base n=702]

Satisfaction with clinical support

Satisfaction scores in 2026 have plateaued at 2022 levels



Feeling isolated and unsupported by NHS

I feel (& am) completely on my own with this. Have not seen a consultant or specialist nurse for over 8 years and only have blood tests intermittently. I often have to contact them to ask if I might be due one. Specialist nurse very pleasant but only reads off blood numbers.

So pleased I found CLL Health Unlocked forum and CLL Support I have gained a wealth of priceless information. I wouldn't be half as confident without it so immensely grateful. I told my consultant there are so many newly diagnosed people on the forum that are completely panicked by a diagnosis and no advice or reassurance, and she totally agrees and said it is a failing definitely.

Very little support from GP. Just a Full Blood Count every 12 months, with no feedback other than online test results. CLL Support online is good but more info from GP is needed

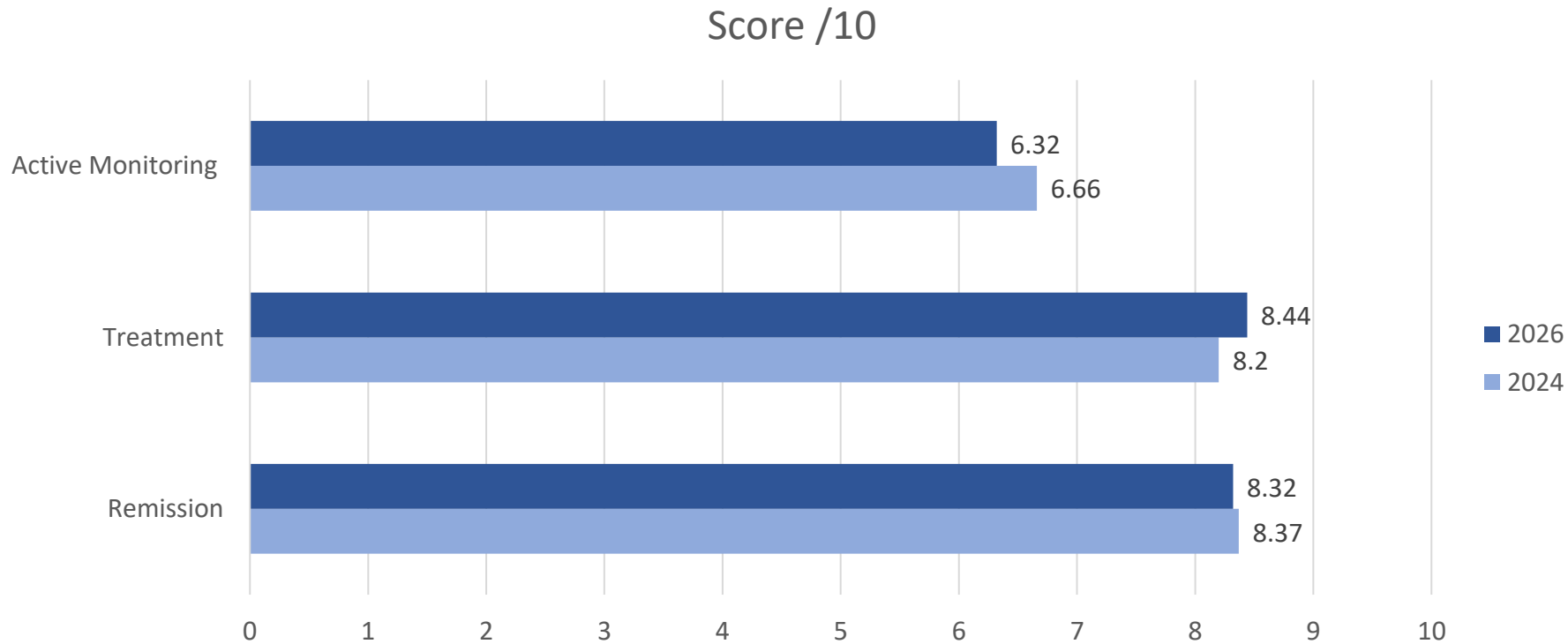
I feel very unsupported by my GP and GP/nursing team. For the first time this spring, I had to push hard to get Covid vaccine

I have had terrible support from the hospital, and feel very alone and just left to die

I'm not sure that CLL SA have ever understood that there are CLL sufferers who have only ever been dismissed by GPs with comments like "There are other people worse off than you", as I have been several times. Now they don't even contact me with blood test results. I have to review them myself on the NHS app.

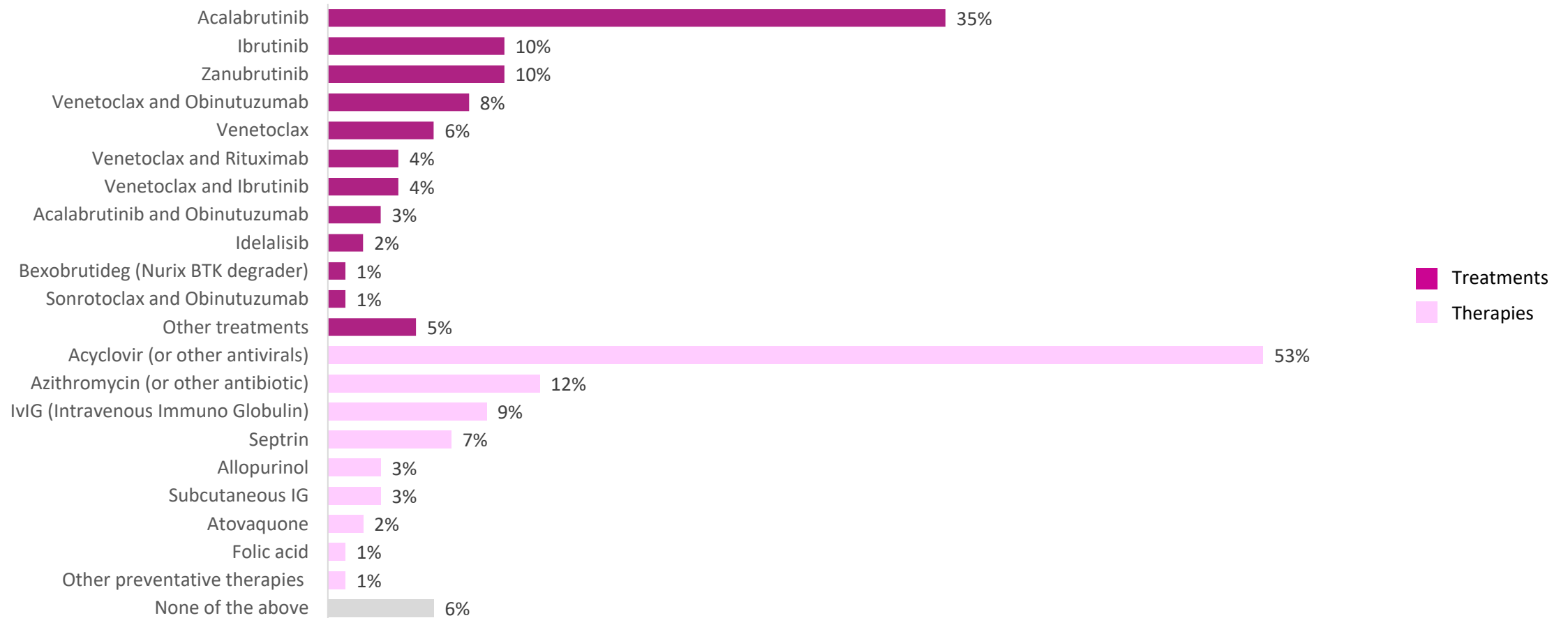
How well informed about treatment

Respondents on Active Monitoring feel less well informed about treatment and all scores are comparable to 2024



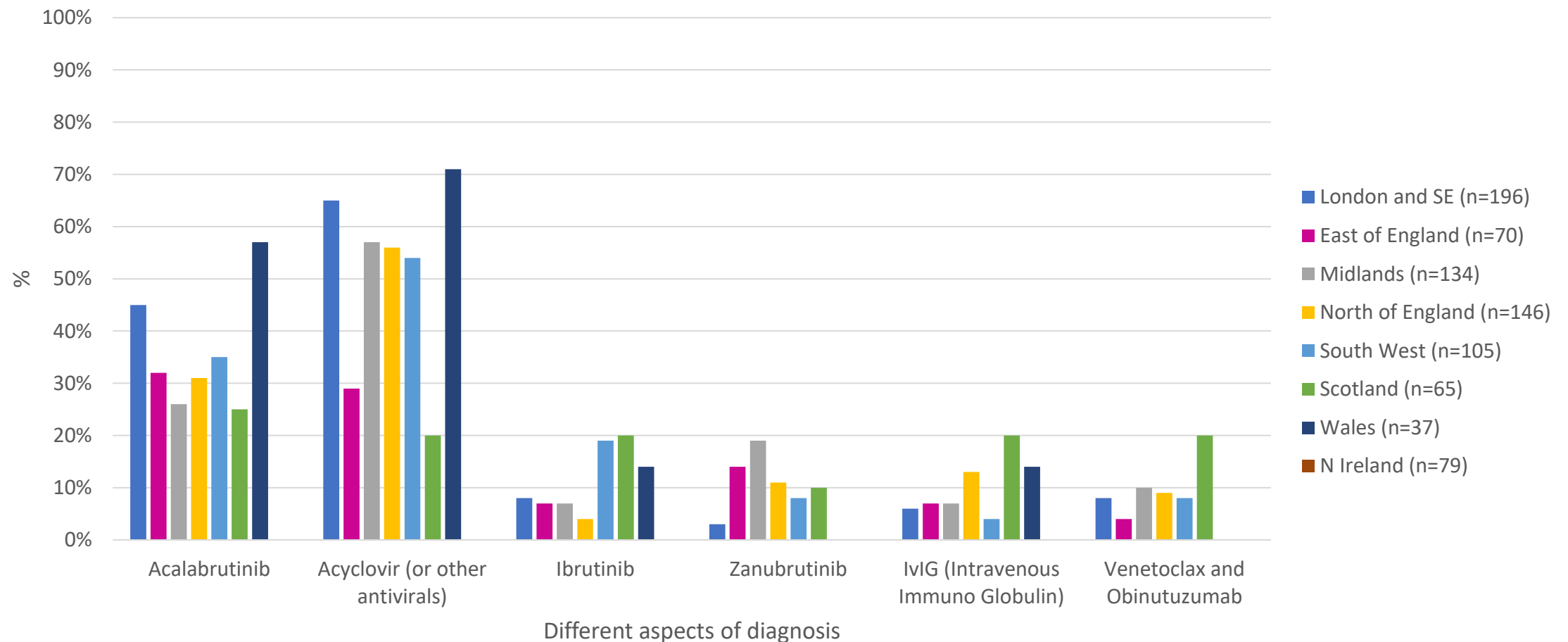
Treatments or therapies received: 2026

Of those who reported being on treatment or therapy, the most common was Acyclovir and other antivirals



Treatments received

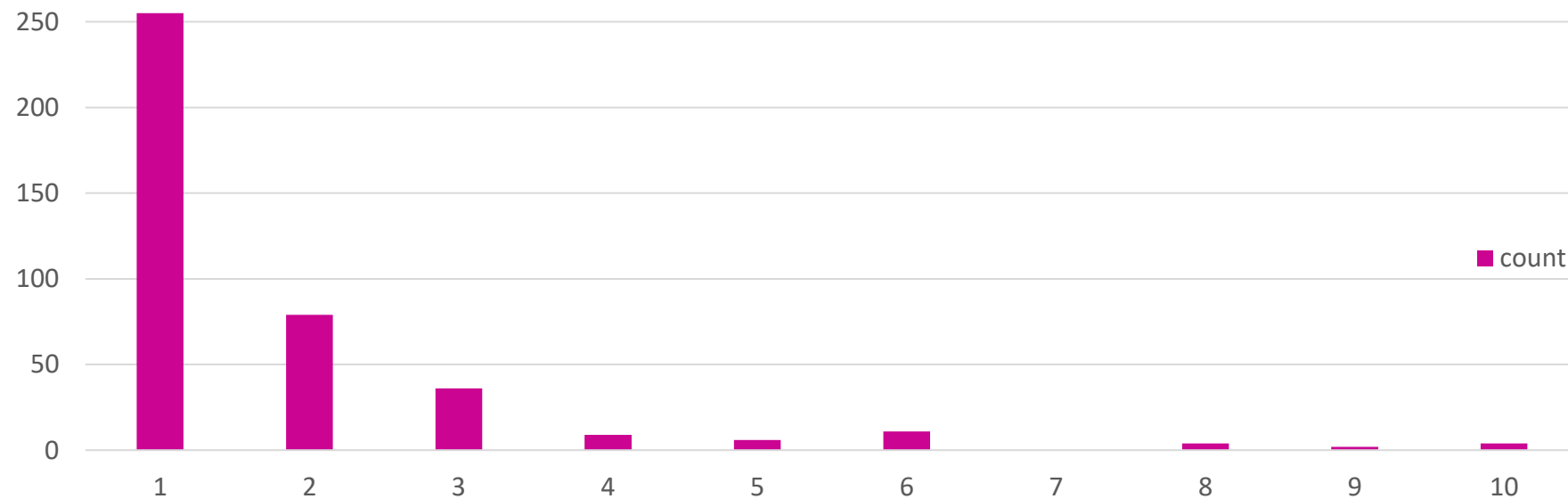
No real geographical differences seen – only that Acalabrutinib was prescribed more in London and SE vs the Midlands, and Zanubrutinib was prescribed more in the Midlands vs London and SE



Lines of treatment received

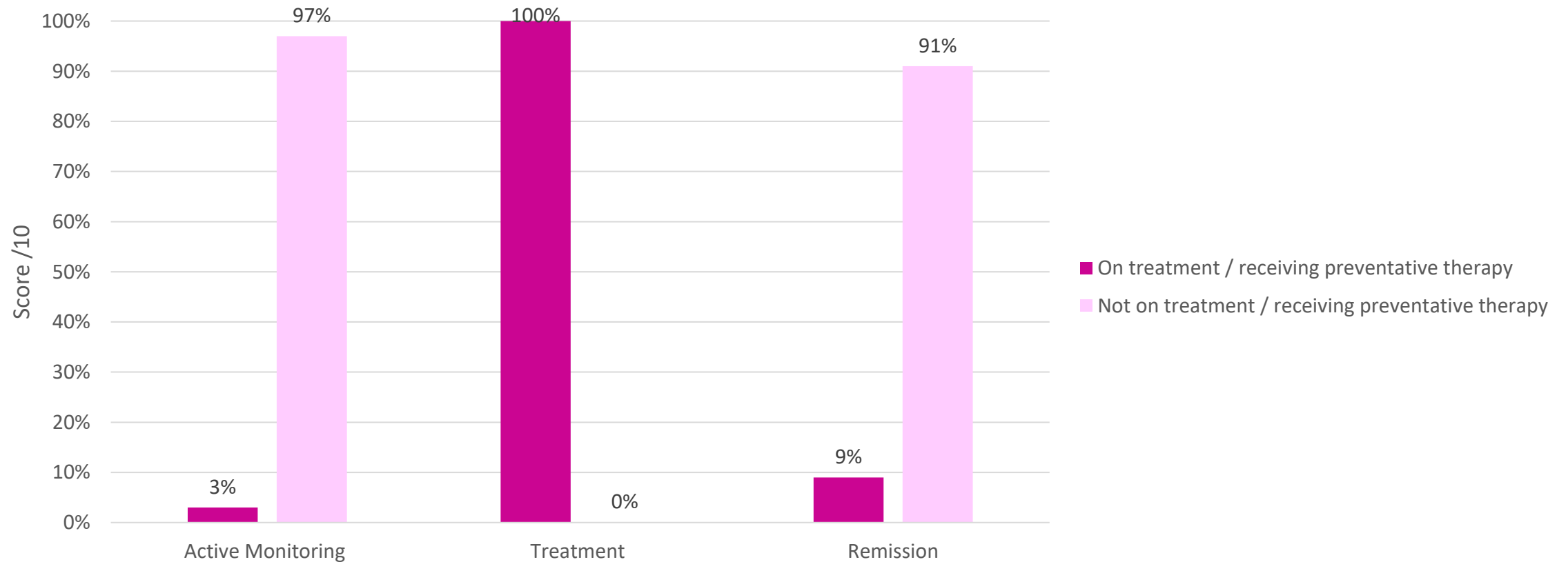
Of those who had had treatment, most (61%) had had a single line of treatment, 19% had had 2 lines of treatment and 9% had had 3 lines of treatment

Number of people on 'x' number of lines of treatment



Currently on treatment or receiving preventative therapy

A small proportion of respondents on active monitoring and remission respectively (3 & 9%) reported they were currently receiving a preventative therapy.



Most respondents said they had received a flu vaccination in the past year

Scotland sig less likely to be vaccinated against flu in the past year than London/SE, East, Midlands and North of England, & Scottish respondents more likely vs London, East, Midlands and North of England to have had none of these vaccinations



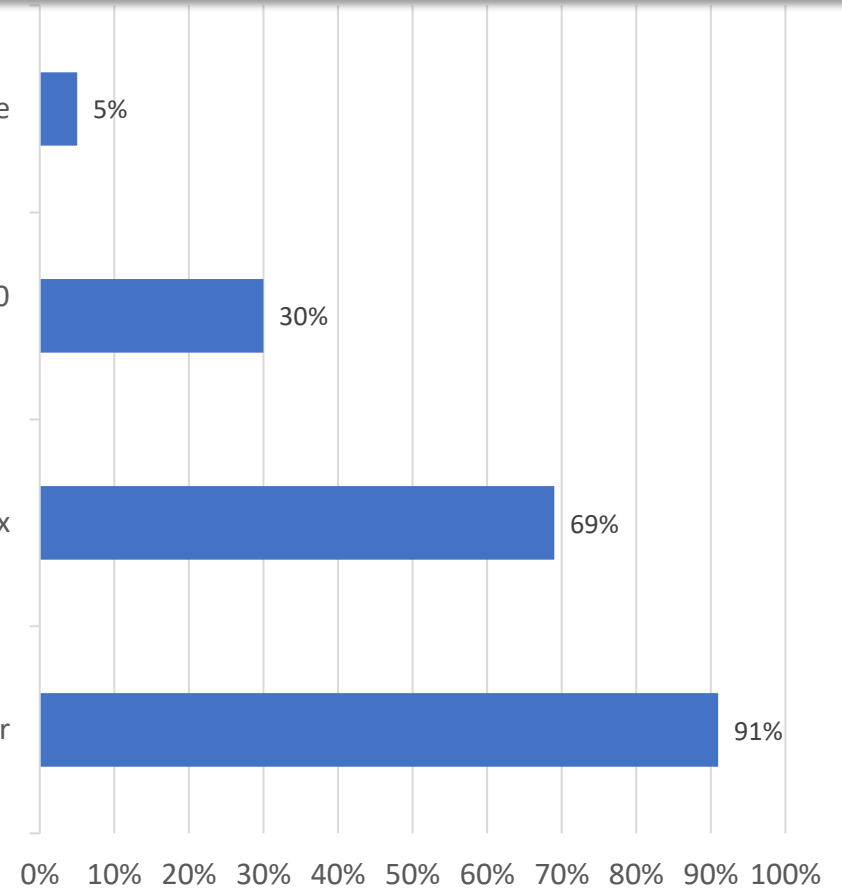
Mean score for how well -
informed respondents feel about
which vaccinations are important:
7.7/10 (similar score to 2024)

RSV vaccine in the last 2 years (available to those 75-80
years old from the NHS)

Flu vaccination in past year

None of these

Shingrix

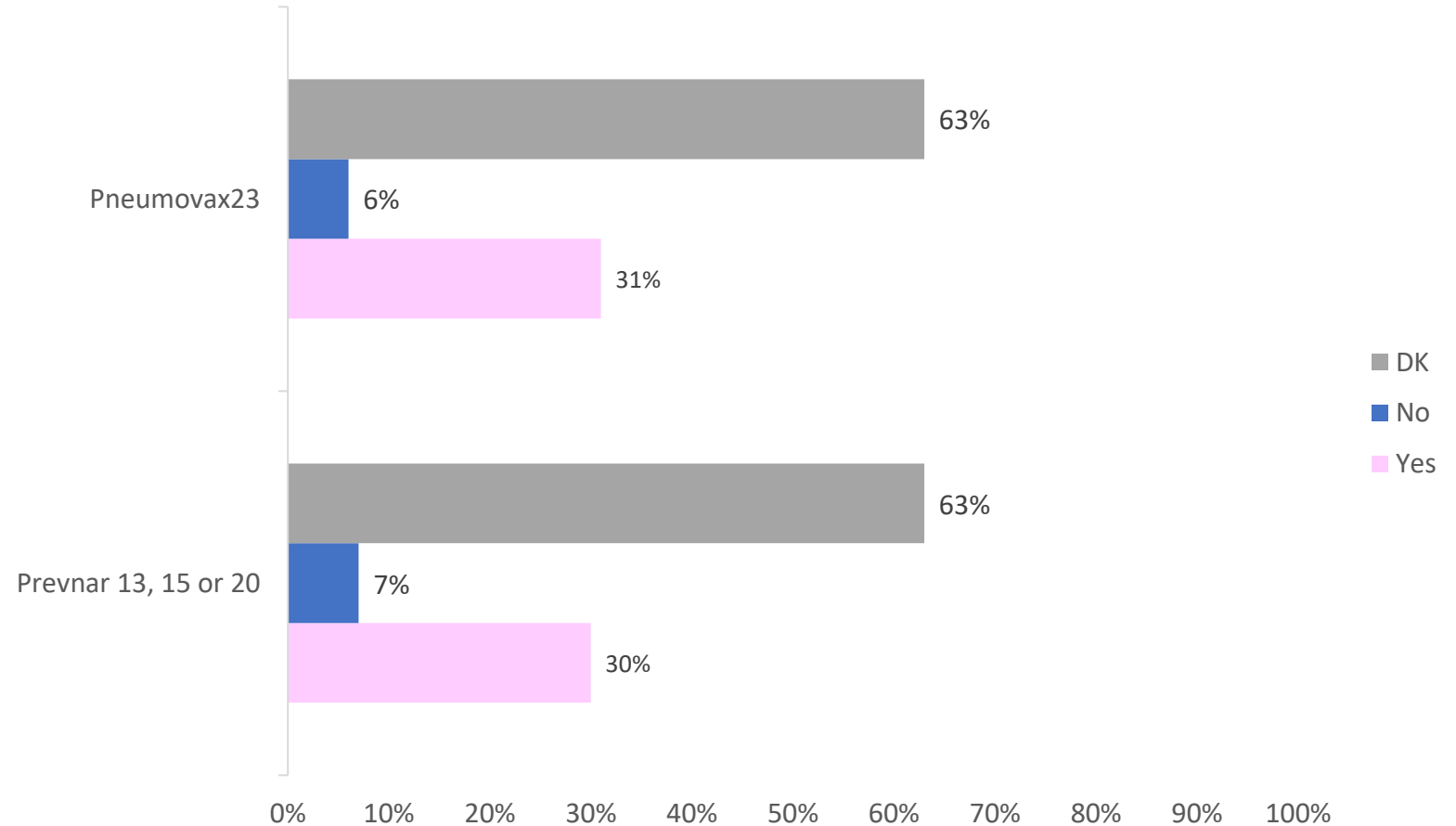


Pneumonia Vaccinations

Of those who knew which pneumonia vaccine they had received, the split between Pneumovax23 and Prevnar was fairly even – but the majority did not know which vaccine they had received



78% of the sample had been vaccinated against pneumonia



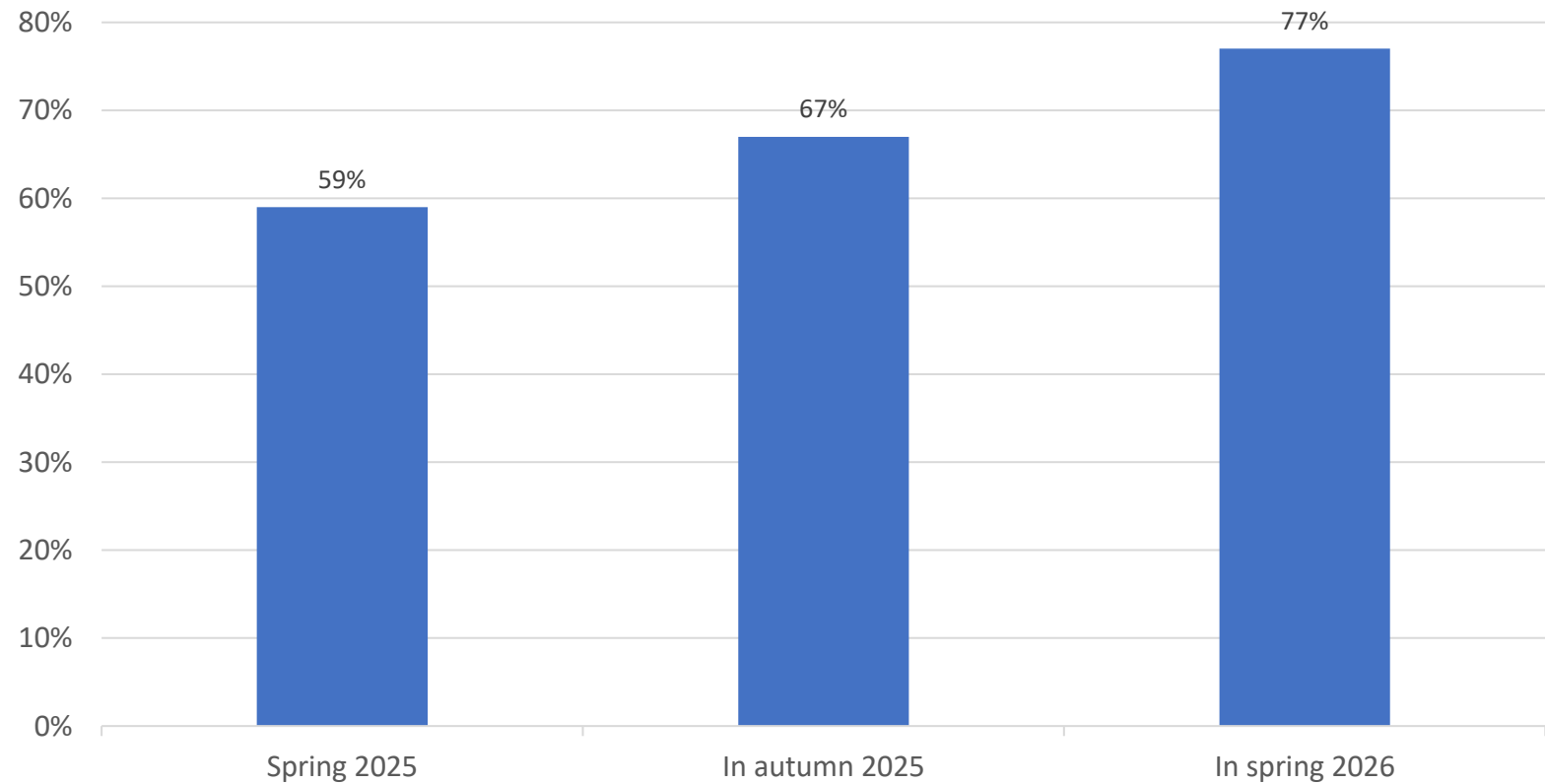


CLL SUPPORT Covid Vaccinations

Numbers taking Covid vaccines have increased in the past year



82% of the sample had been vaccinated against Covid in the past 15 months



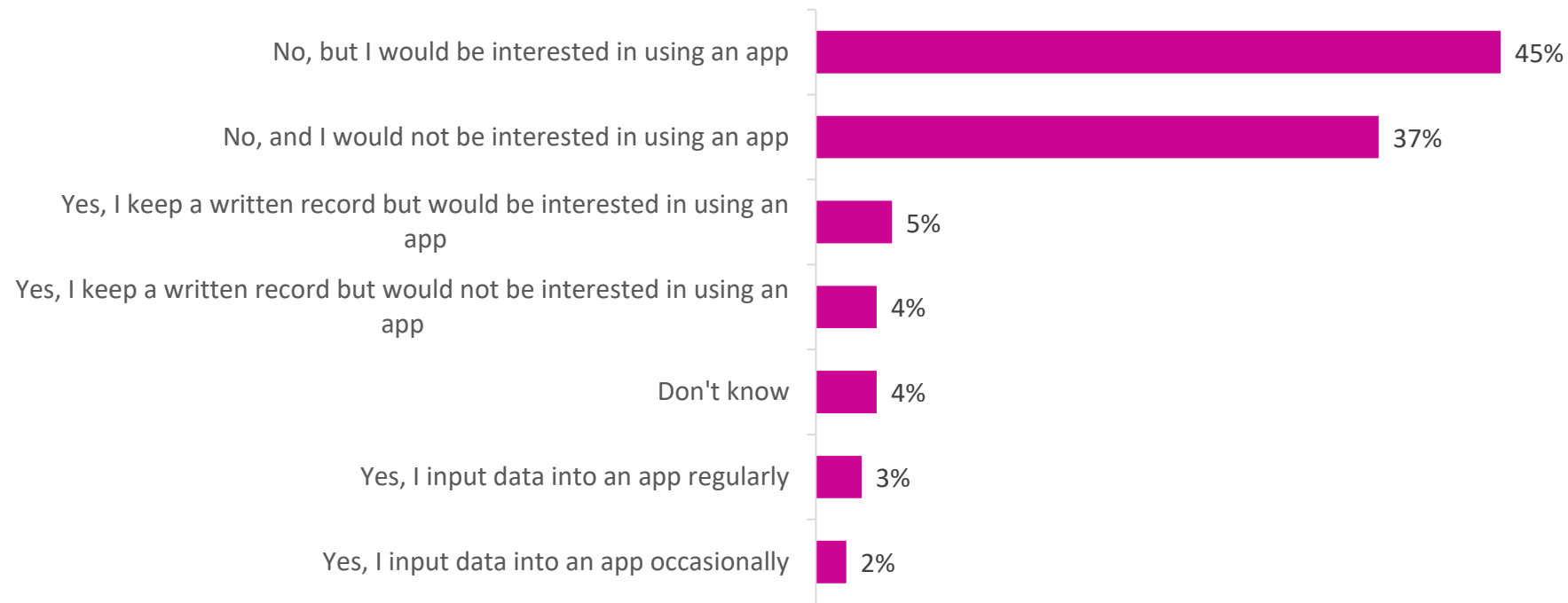
QV13b1. Have you had any Covid vaccines in the past fifteen months? [Base n=894]

QV13b2. When were you vaccinated? [Base, those who had a Covid vaccine in the past 15 months: n=736]

Recording symptoms or wellbeing: 2026 Survey

Only a minority of respondents currently record how they are feeling, but nearly half the sample would be interested in using an app to do this

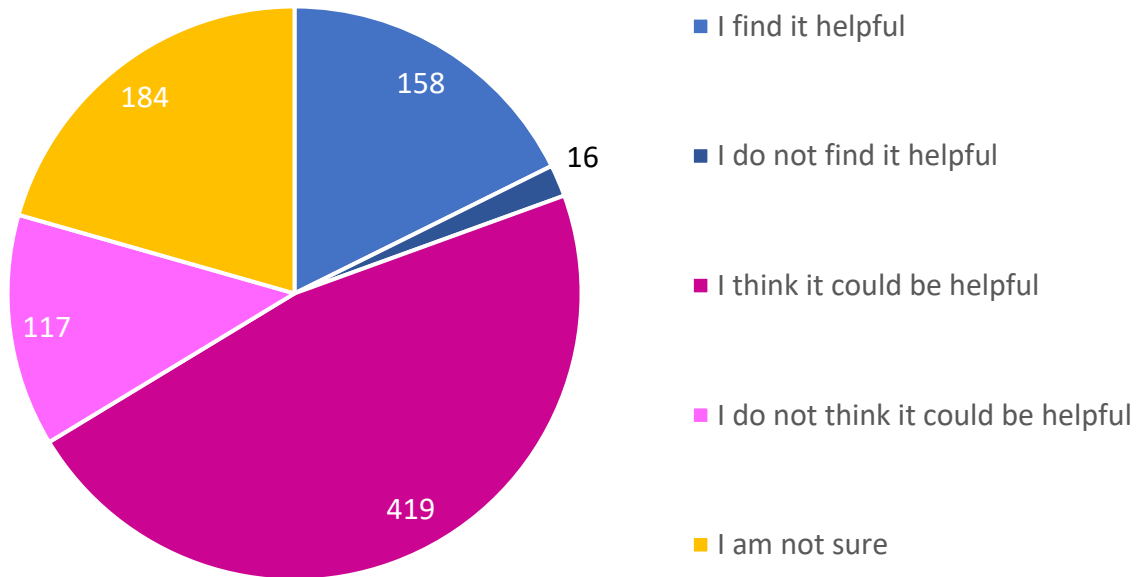
Do you record how you are feeling?



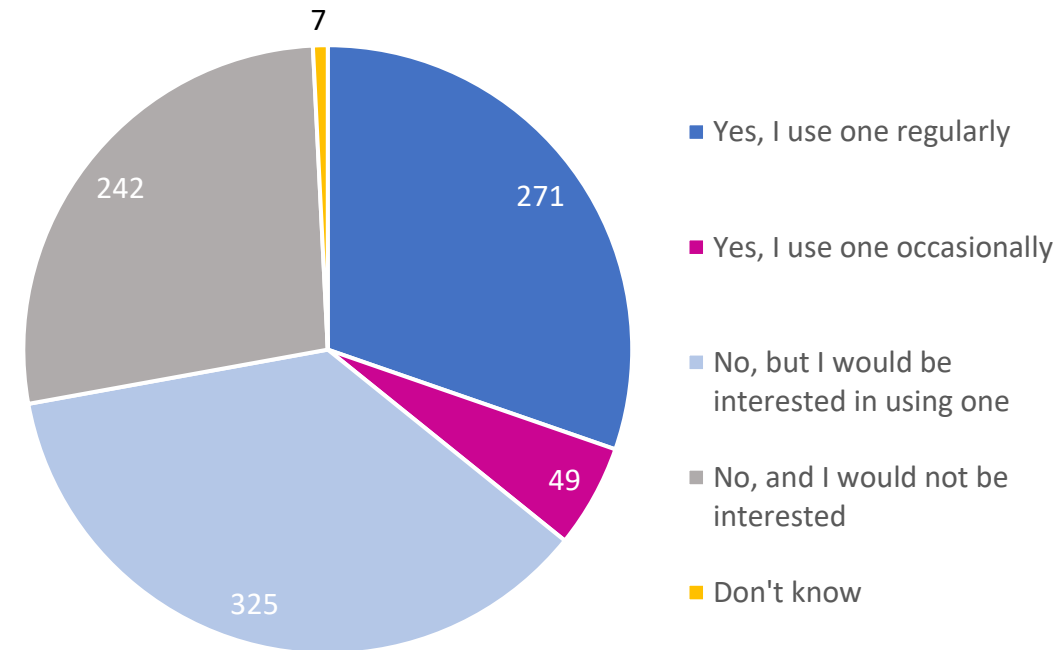
Apps and Wearable devices

Overall, there appears to be an interest in using apps and wearable devices to support life with SLL/CLL

How do you feel about using technology to help manage life with CLL/SLL?



Do you use a wearable device?





CLL Support

Respondent feedback on the value and impact of CLL Support

“

So pleased I found CLL Health Unlocked forum and CLL Support I have gained a wealth of priceless information. I wouldn't be half as confident without it [I'm] so immensely grateful

I think CLL Support is a great organisation, well run and always evidence based in their approach to support and information

I could not have been better supported by CLL Support

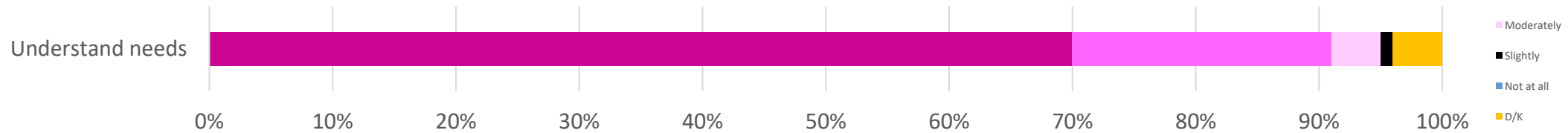
I have gained most of my CLL knowledge from this platform

”

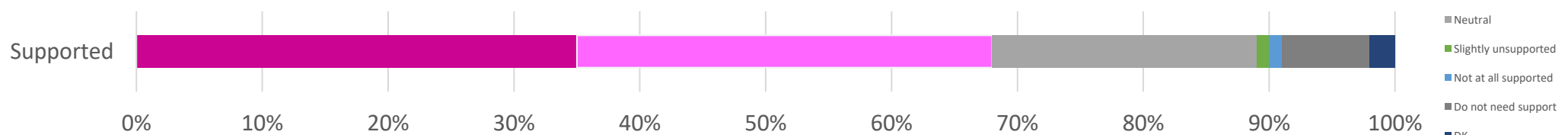
Level that members feel their needs are understood and supported, and have confidence in CLL Support

91% of respondents felt that CLL Support understand the needs very/quite well, 69% felt either very/quite supported and 90% were very/quite confident that interests were well represented

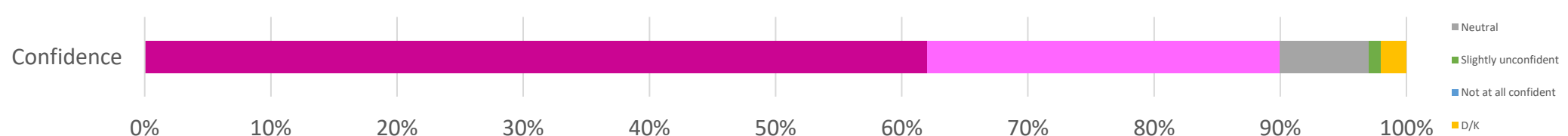
CLL Support understands the needs of people affected



Extent to which feel supported by CLL Support



Confidence that CLL Support represents the interests of people affected by CLL



Comments on CLL Support : *“Just being there is making me feel safer”* and filling knowledge gaps

I don't always use the services of CLL Support but I know it's there when I need it and that is so important.

Very grateful to have access to CLL Support and all the resources that it provides - the clue is in the name!

I have learnt so much about CLL by belonging to CLL Support that has helped me to understand and manage my condition. Been given the chance to meet others diagnosed with CLL

I am so grateful for CLL Support as it plugs the gaps from the GP and hospitals' shortcomings

I have rung CLL Support twice and was very impressed by the support I was given. I am quite dismayed by the lack of knowledge of CLL by my GP and the surgery , and by the feedback I receive after 6 monthly bloodtests. Lack of interest and knowledge of the condition

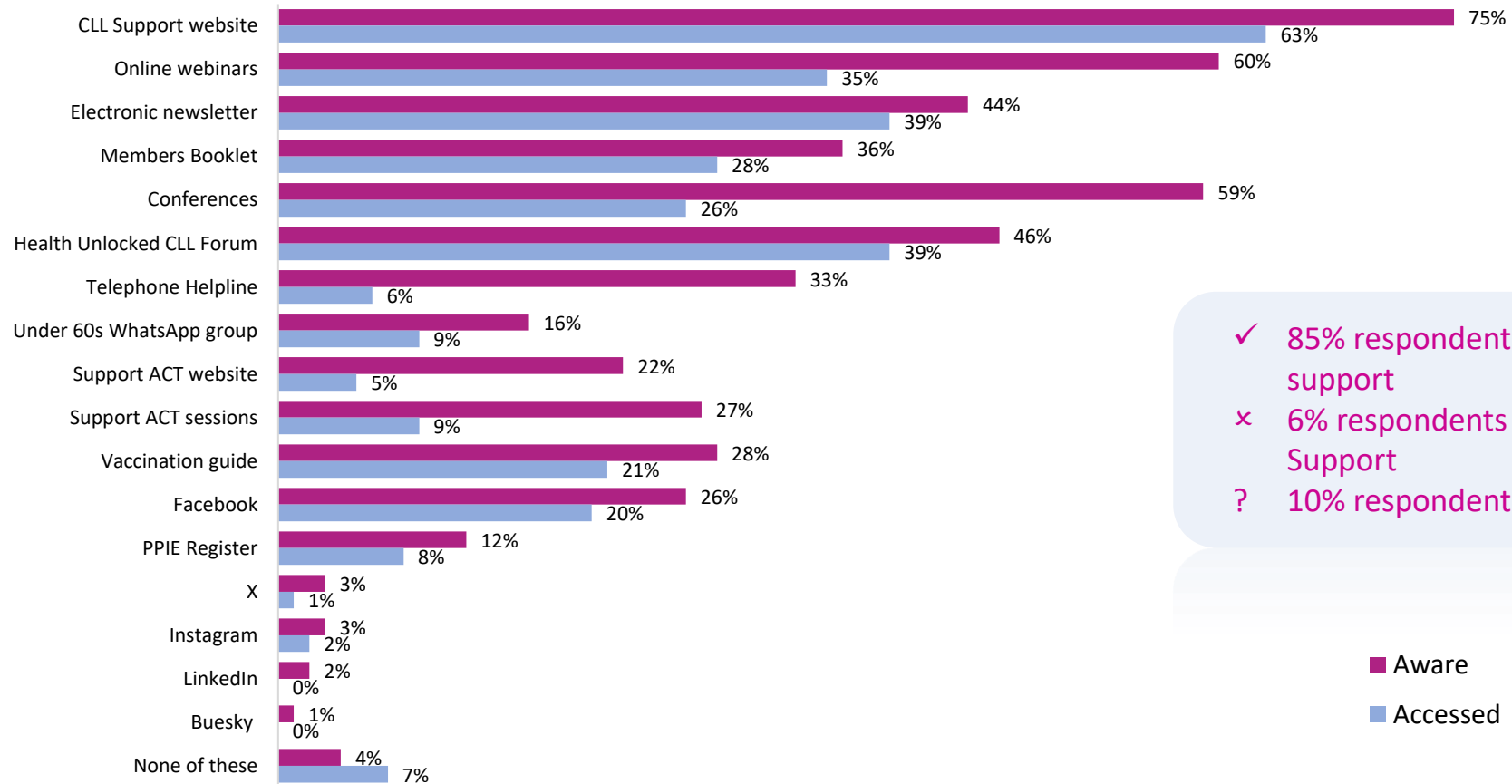
I found CLL Support very useful during the active monitoring and treatment phases. Now that I am in remission, less so. But when CLL returns I will know where to find support

After leaving my diagnosis appointment with no knowledge, I have been thoroughly educated by CLL support and my mental health has improved.

I have gained most of my CLL knowledge from this platform.

Service awareness and access: 2026 Survey

Awareness and access was highest for the CLL Support website. Although most respondents were aware of the webinars and conferences, approximately a third had accessed them.



- ✓ 85% respondents are members of CLL support
- ✗ 6% respondents are not members of CLL Support
- ? 10% respondents do not know

■ Aware
■ Accessed

Q17. As far as you know, are you a member of CLL Support? [Base n=894]

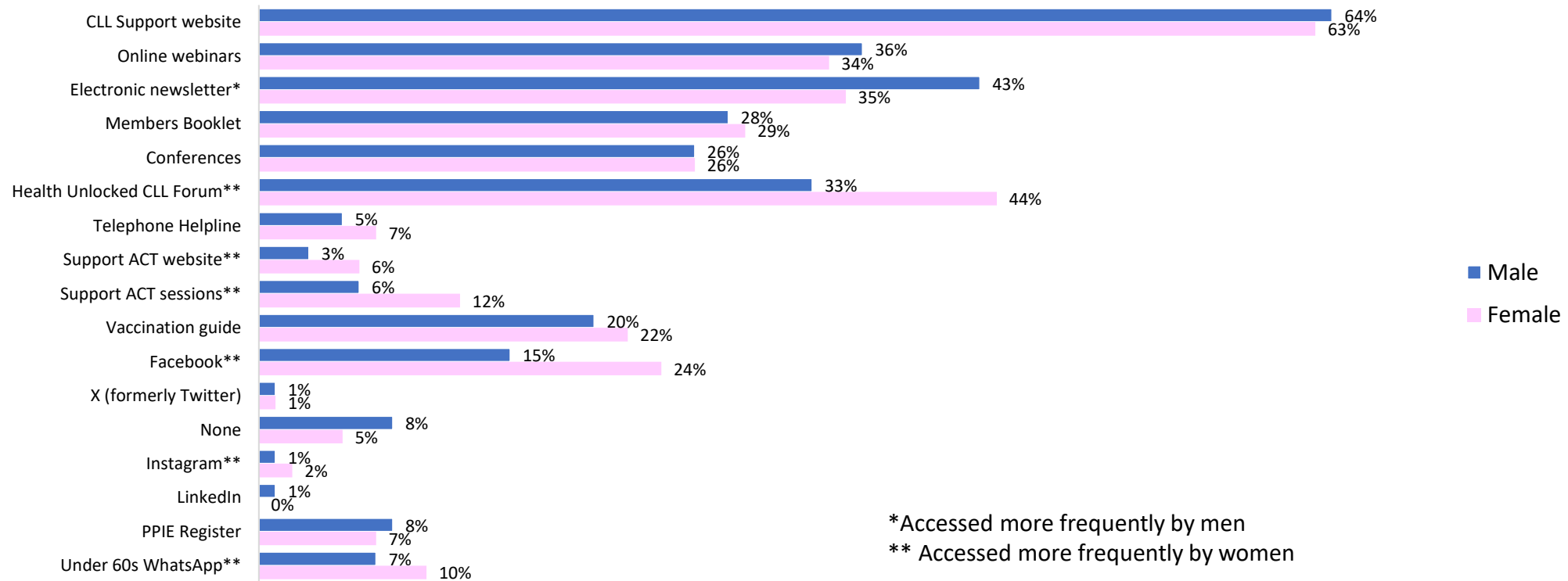
Q18a. Which of the following CLL Support services are you aware of? [Base n=894]

Q18b. Which of the following CLL Support services have you accessed? [Base n=894]

Access to CLL Support services by gender: 2026 Survey

Access to CLL services was generally comparable across men and women but male respondents were more likely to access the electronic newsletter, and women female respondents were more engaged with Health Unlocked, Facebook, Under 60s WhatsApp and Support ACT

Which CLL support services have you accessed?



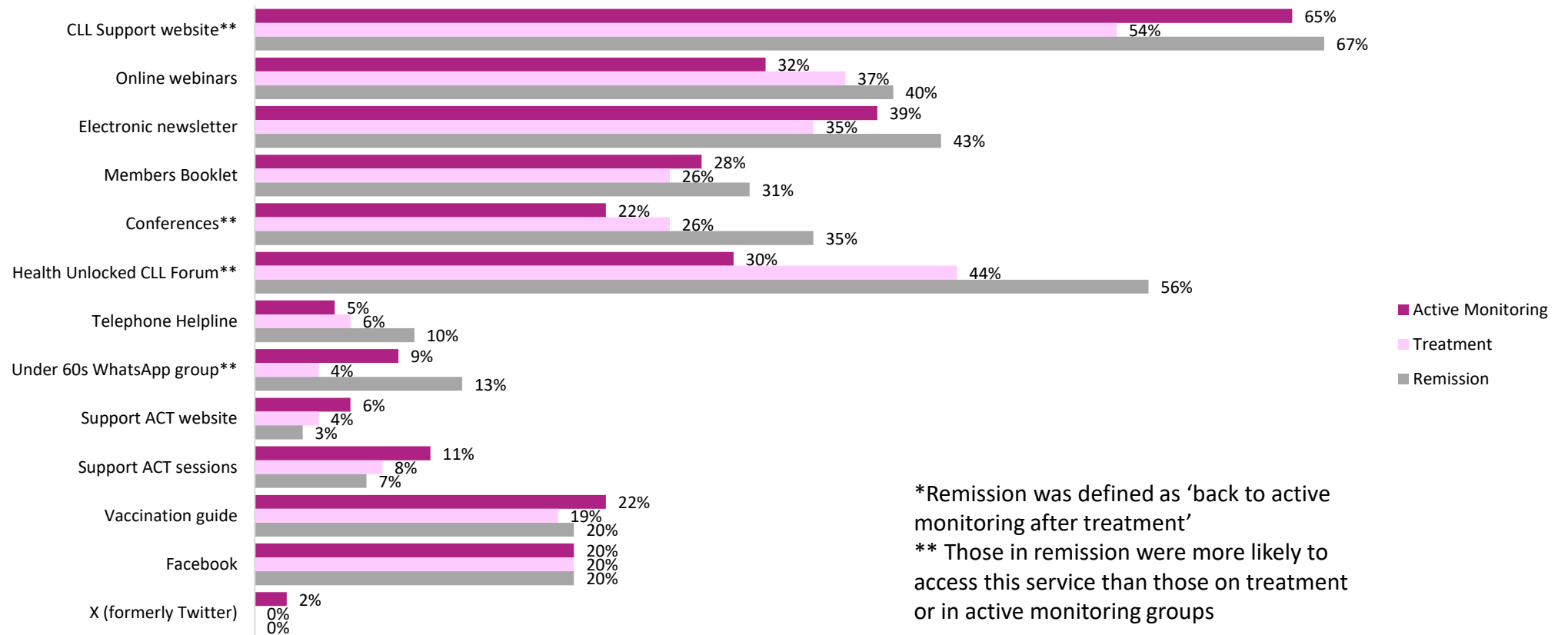
Q20. What is your gender? [Base n=894]

Q17. As far as you know, are you a member of CLL Support? [Base, Members: n=894]

Q18b. And which of these CLL Support services have you accessed? [Those who are aware; Base n=859]

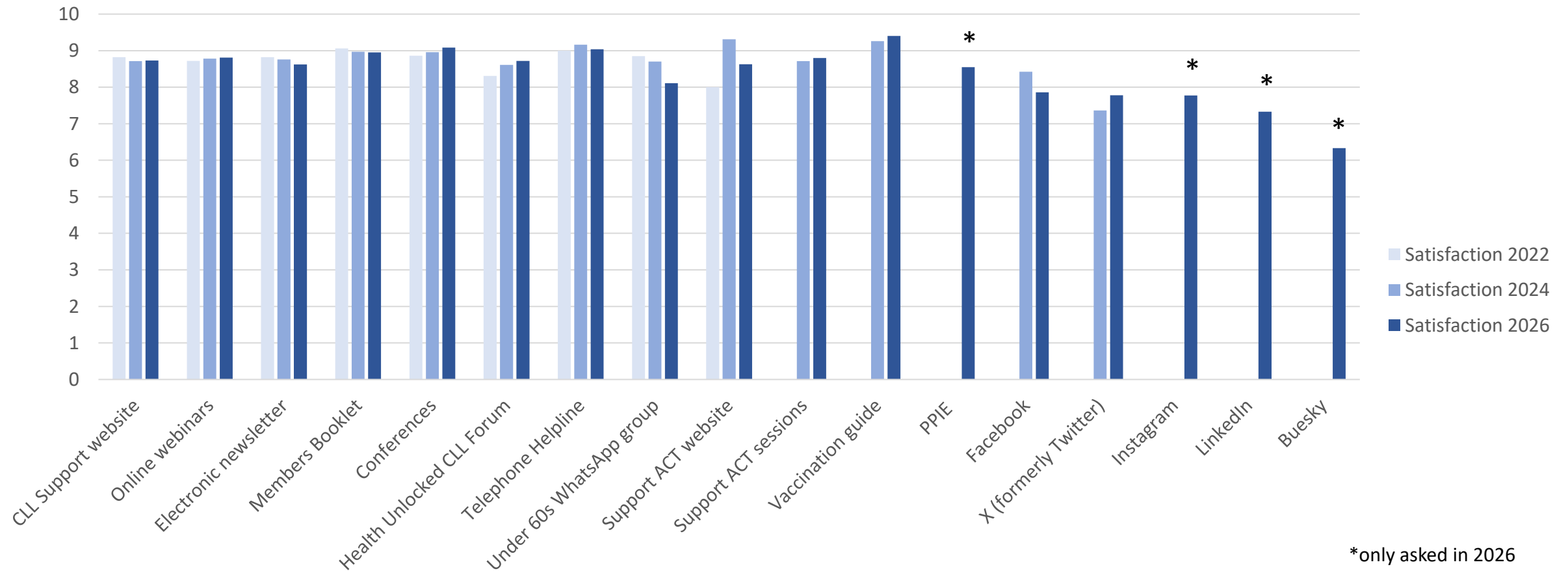
Access to CLL Support services by stage: 2026 Survey

Respondents in remission appear to be most active in accessing the CLL Support website, Health Unlocked CLL Forum, conferences, the Under 60s WhatsApp group and the telephone helpline



Level of satisfaction with CLL Support services

High levels of satisfaction were reported across all services offered, and with a notable score against the PPIE (Patient and Public Involvement and Engagement) Register



*only asked in 2026

Comments on CLL Support: hugely appreciated

Health Unlocked is amazing - and it was my consultant who recommended on diagnosis that I got in touch with CLL Support.

Use HealthUnlocked, all the information is there

The Health Unlocked CLL community has been EXTREMELY helpful and supportive for me

Health Unlocked invaluable

The under 60's WhatsApp group is brilliant for me - I don't contribute much, but I read the messages. I try to attend one conference per year and these have been excellent - very informative, reassuring, and a good chance to get updated on the latest CLL and speak to other sufferers who are in the same situation as me.

Webinars and speakers are superb and is where I get the most information from

I have found the support sessions very helpful. It's lovely to 'meet' people like Pinky and Hilary. Thank you for those.

CLL Support **vaccination guide** (and Oxford L-68) was vital in getting PCV13 after treatment and 2 years after PVV23. At diagnosis and before treatment two consultants said they encouraged me to get vaccinated but were unable to tell me what vaccinations were needed



CLL Support is very grateful to Dr Bee Laird and to Keith at Research Interactive for their help with this survey.

We are indebted to the following pharmaceutical companies for the financial support they have provided towards the costs of preparing and analysing the CLL Support 2026 surveys. They have had no input into the content of the surveys.

abbvie



AstraZeneca



BeOne



Lilly