

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

Second National CLL Survey: March – April 2024

First National CLL Survey: May - June 2022

Why we did the survey

CLL Support repeated the survey in its 20th Anniversary year so we can:

- 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
- provide the services and support members of CLL Support and their partners, family, carers and friends most value
- We were keen to compare the results with those from two years ago

Methodology

As we are a patient-led charity, we invited patients in the UK with CLL or SLL and their partners and family, carers and close friends to complete the survey.

The link to the survey was shared (with several follow up reminders)

- (i) by email invitation to members inviting them to participate
- (ii) on the CLL Support Under 60s WhatsApp Group
- (iii) through Facebook, Instagram and X (was Twitter)...

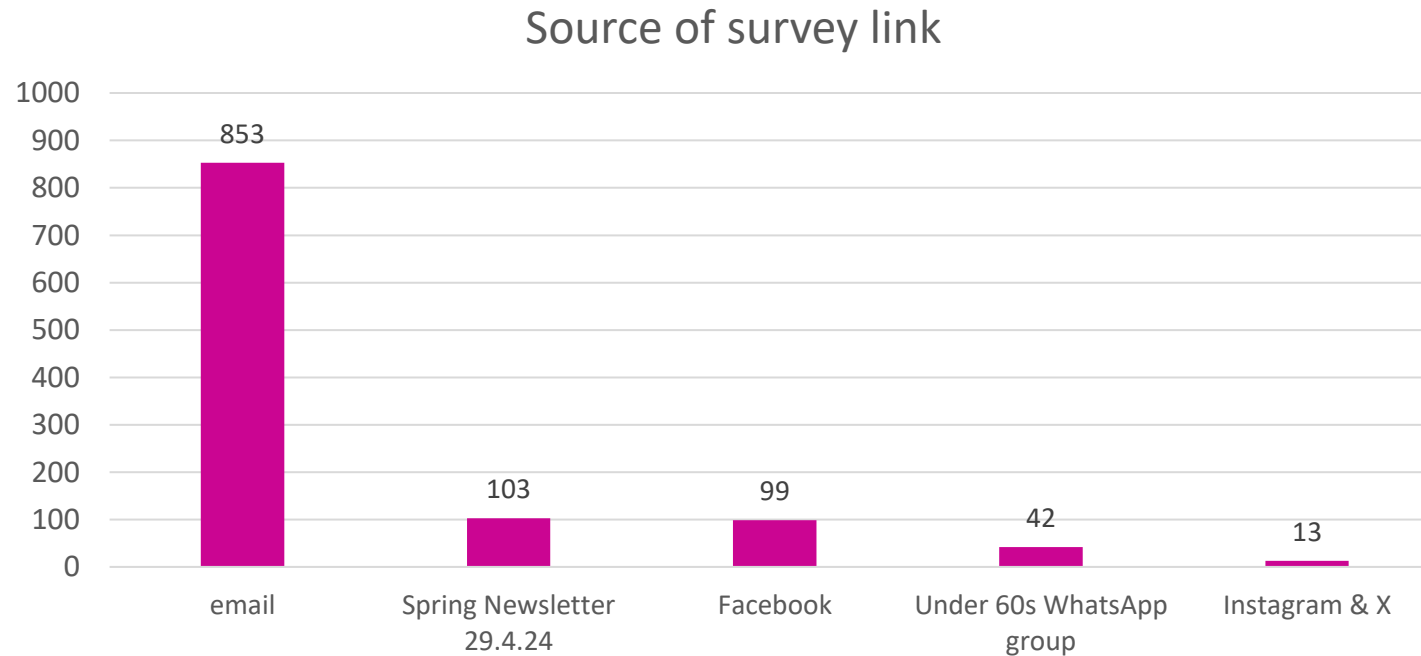
We received 1110 responses (702 in 2022)

All information was provided on an anonymous basis

Sample

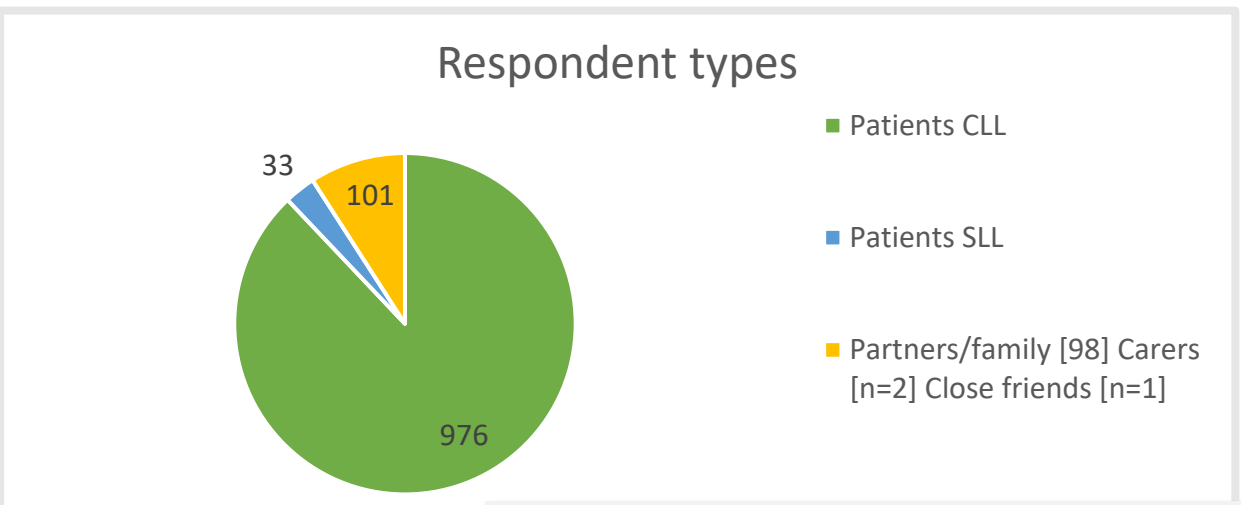
Respondents: 1110 people completed the short survey

The vast majority of respondents responded to the ask to complete the survey via a link emailed to members. The Spring Newsletter and Facebook were the next most successful routes to contacting respondents. 408 more respondents answered the survey in 2024.

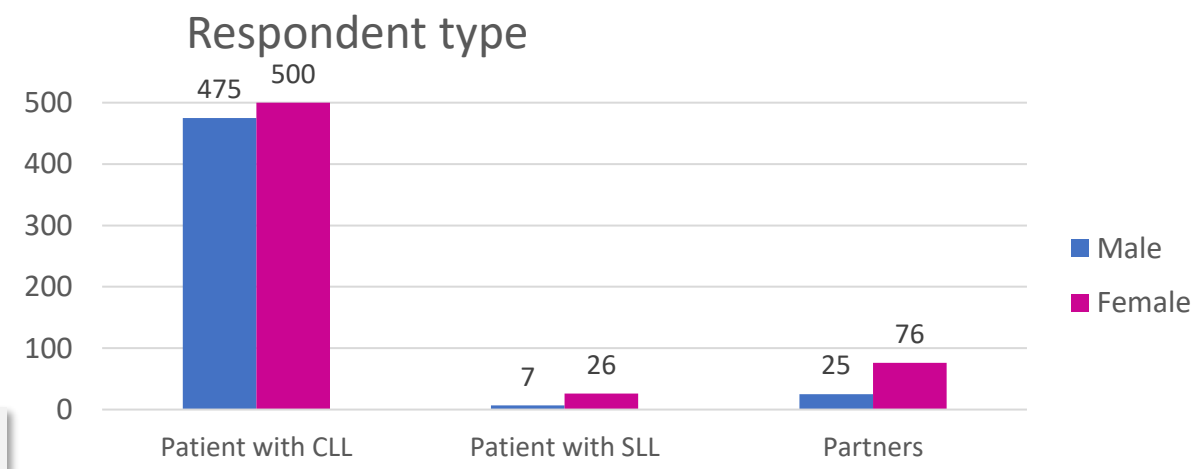
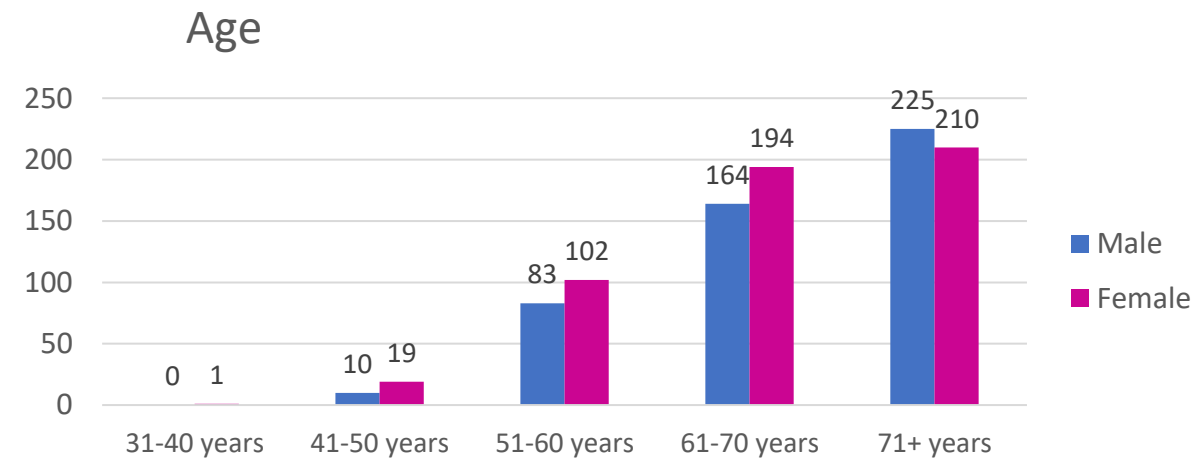


Respondents: details

As in 2022, slightly more women than men answered the survey, which may simply reflect the membership of CLL Support, which is weighted towards women, and potentially highlights a need for support to appeal more to men. The majority of respondents were patients in their 60's and 70's.



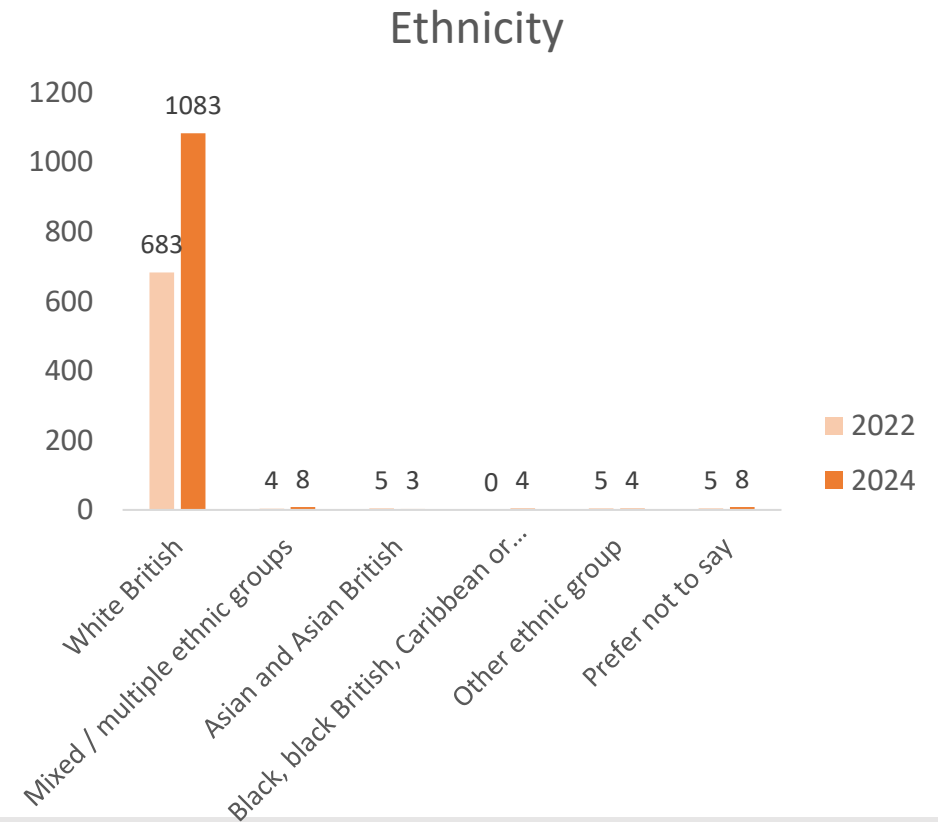
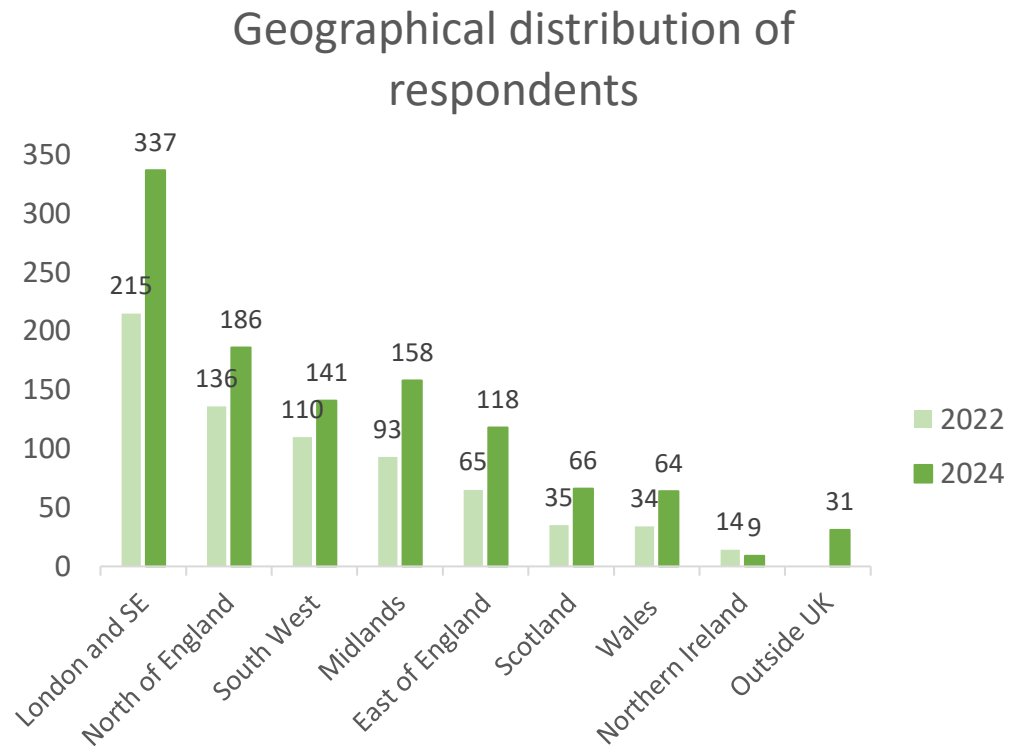
Partners, carers and close friends grouped together & referenced as “partners” for the rest of the survey



S1. Please indicate whether you have been diagnosed with CLL/SLL or whether you are the partner or family member / carer / close friend of someone who has been diagnosed with CLL/SLL? [Base, patients n=1008]; Q19. Into which of the following age groups do you fall? [Base n=1110]; Q20. What is your gender? [Base n=1110]

Geographical distribution of respondents

As in 2022, most respondents were from London and the SE, but all regions were represented including outside the UK



Q22. Which region do you live in? [Base n=1110]

Q21. What ethnicity are you? [Base n=1110]

In summary

Summary of 2024 learnings

- Impact on QOL is high in all respondents, across all stages of treatment
- Family/caregivers rate higher emotional & physical impact of CLL / SLL vs. those they care for diagnosed with CLL / SLL

High impact on quality of life



- Women are accessing more CLL Support Services

Accessing services



- SLL is only 3% of the total respondent sample, and CLL is 88% of the sample

CLL dominates the sample



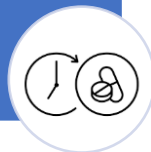
- Fatigue impacts more than half the sample and is the most frequently experienced symptom, across all categories.
- Fatigue is highest in those receiving treatment

High rates of fatigue reported



- Respondents reported excellent adherence to treatment, particularly those more recently diagnosed

Adherence is high



- 2/3 of the sample have had Covid vs. 1/3 of the sample in 2022
- 36% of those who reported they had Covid 19, were told they were not eligible for anti-viral treatment

Majority have had Covid, but a third of those not offered anti-virals



- Nearly half the respondents reported having no comorbidities

Low incidence of comorbidities



- The proportion of face-to-face consultations has increased since 2022
- Overall satisfaction with clinical support has improved since 2022

Clinical support increasingly face-to-face



Compliments from the respondents!



'I'm so glad you are there when I need you'

'Very grateful for the regular newsletter and particularly updates on CLL research/outcomes.'

'I really appreciate the support of CLL Support... learned a lot from their Webinars.'

'Feel fortunate to have CLL support as it empowers me in my dealing with the medics.'

'Health Unlocked is a fantastic, really well-managed resource.'

'I have been massively impressed with the info and support available having only recently been diagnosed.'

'Provides a valuable source of information and support. Conferences are excellent.'

'I would like to say a huge thank you.'



Anything else – open comments



“I find it difficult to cope with the fact I will never get better.”

“CLL are so supportive... the conferences especially the one from Sussex University, with the link between exercise and reducing the effects of CLL - I have now upped my exercise up quite a lot.”

“I would like there to be a bit more discussion about Covid and the current risk levels. As someone who is still shielding, it is difficult to know how high the risk is as the government no longer provides any information. And as far as the public is concerned, Covid is over.”

“It can be hard to explain to people that you do not need treatment because most people I know have never heard CLL so they hear the word cancer and the expect you to be having chemo.”

“Please don't forget that when you give advice that applies to people living in the NHS England geographical area, it may well be wrong if they live a few miles away... in Wales... there is an English NHS, and a Scottish NHS, and an NI NHS - all different.”

“As a partner I feel in the dark about how CLL will affect our lives.”

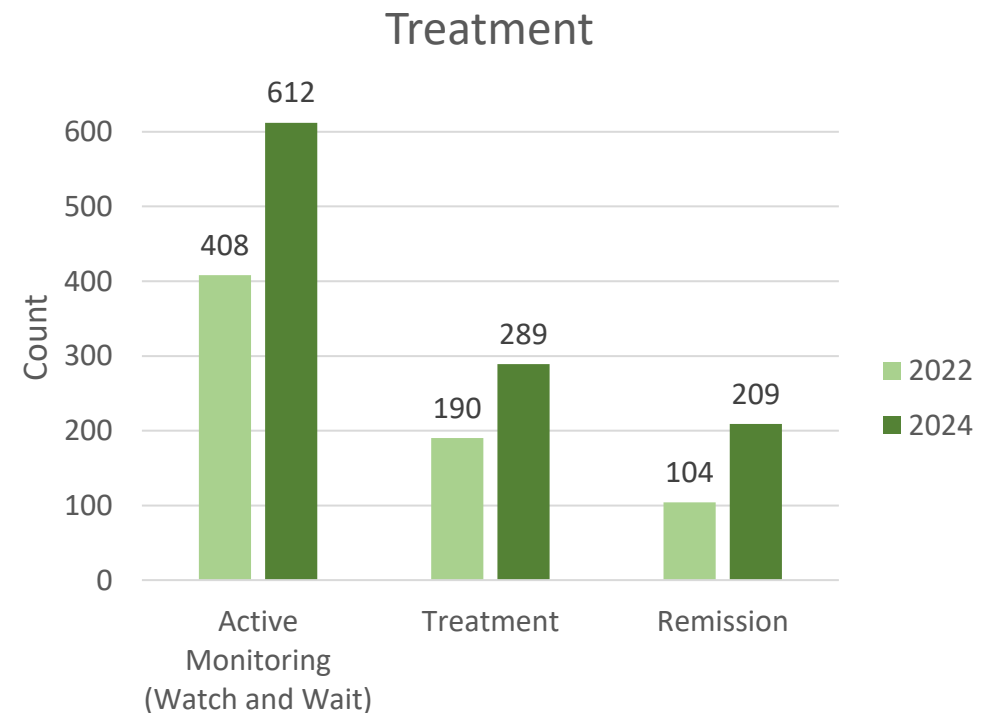
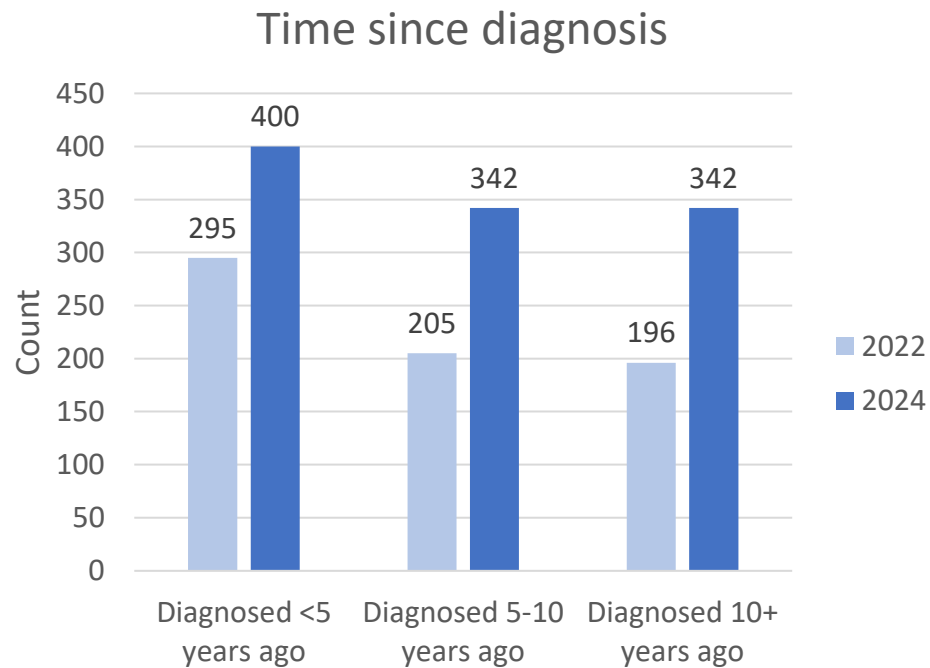
Survey results

Interpreting the results:

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

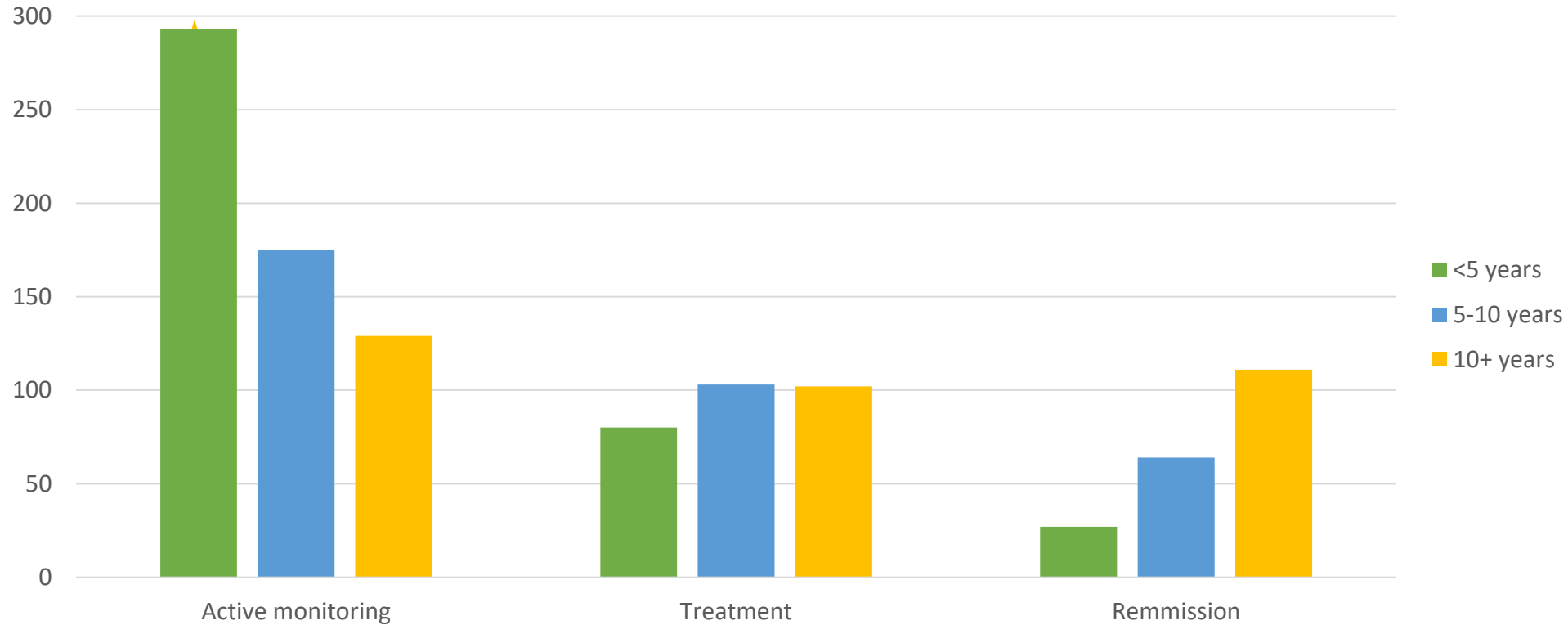
Current situation: 2024 vs 2022

Over a third were diagnosed less than 5 years ago, but those diagnosed longer ago were well represented. More than half were in 'active monitoring', about a third of the sample receiving treatment, less than a fifth in remission



Current situation

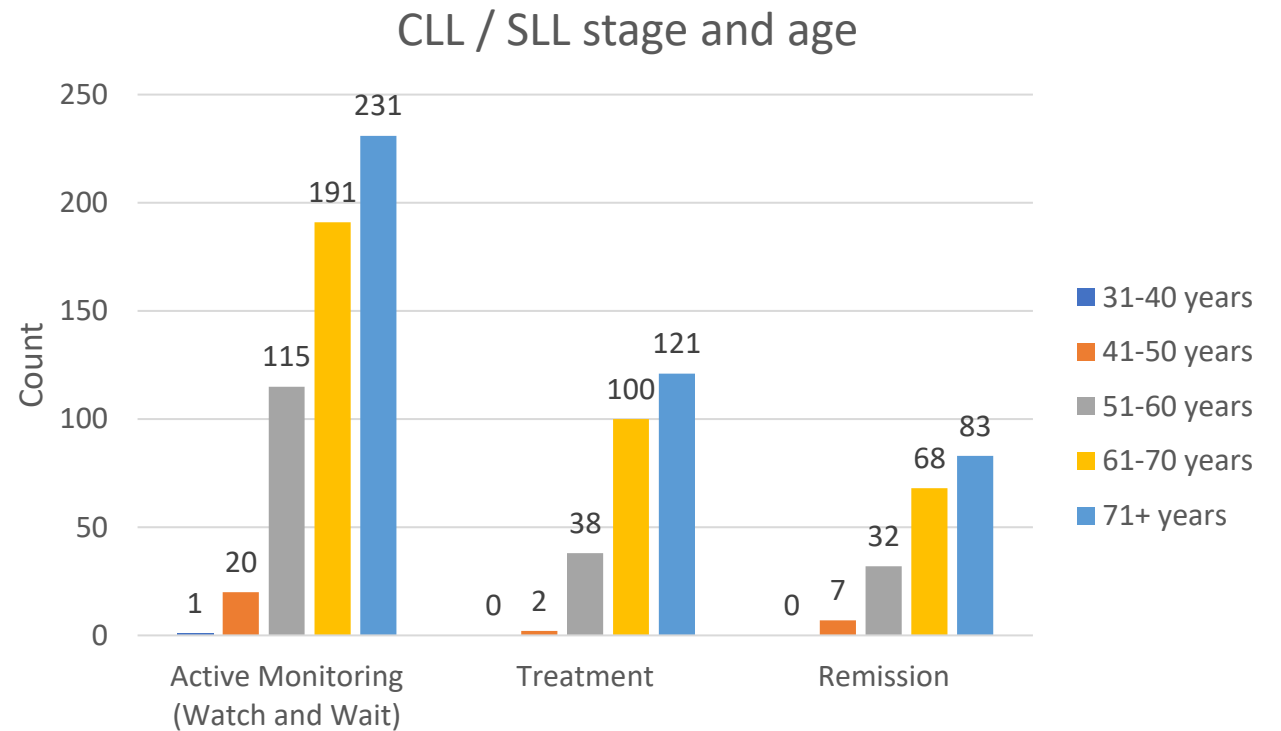
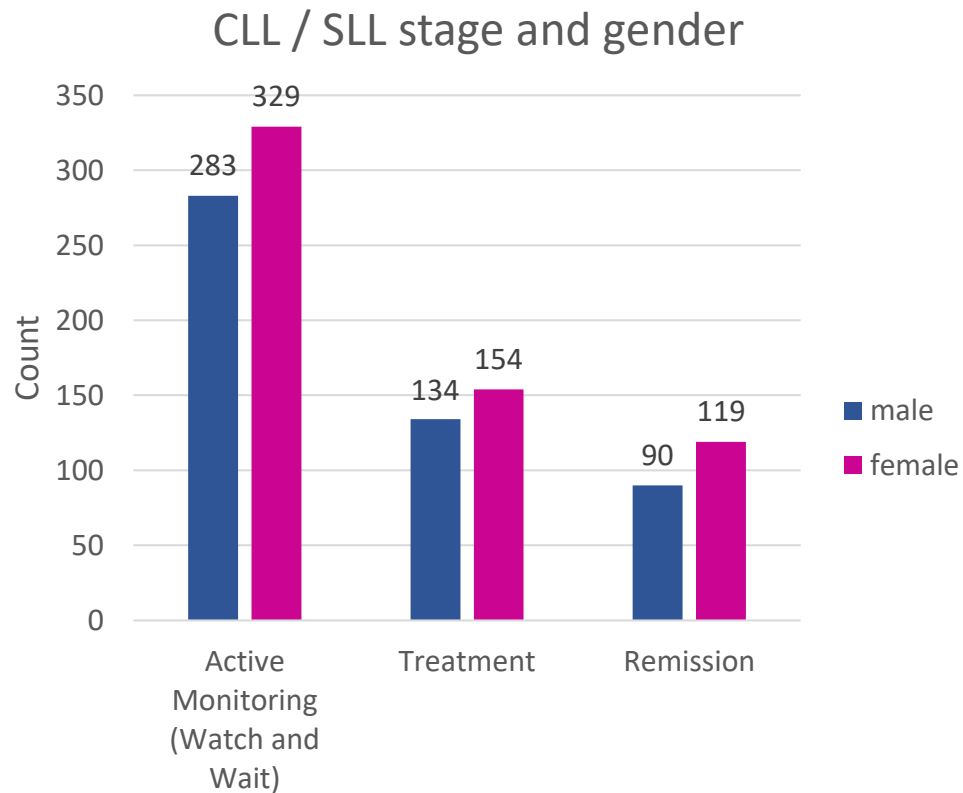
Most respondents were on 'active monitoring'. Of those on treatment, fewest were in the most recently diagnosed group, and more respondents diagnosed over 5 years ago, were in remission.



These figures reflect time since diagnosis

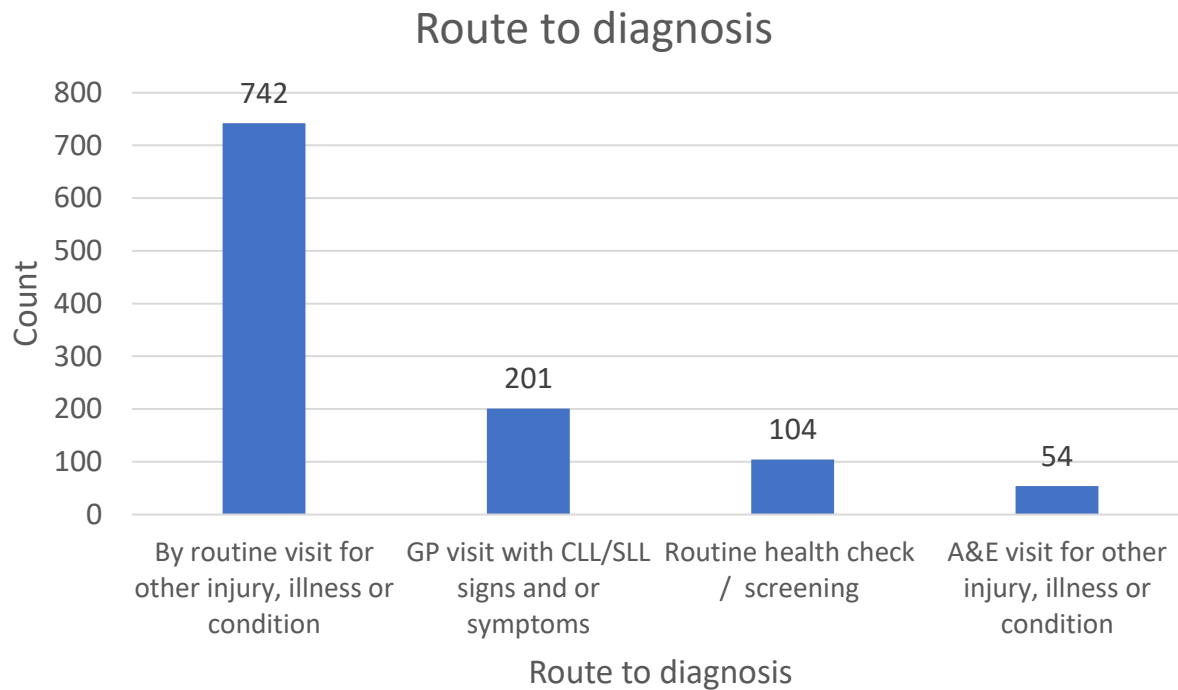
Current situation

No differences of note across age or gender when looking at stage of treatment for CLL/SLL, or across location.

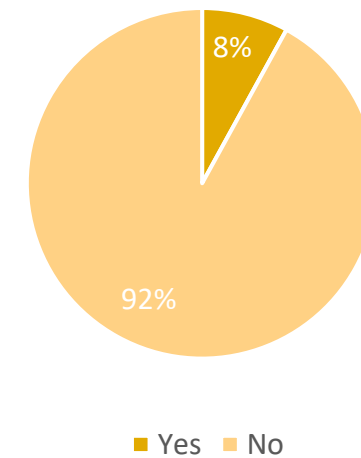


Route to diagnosis

Most respondents were diagnosed incidentally via a routine medical health check for another condition – fewer than 1 in 5 consulted specifically with signs and symptoms of CLL / SLL

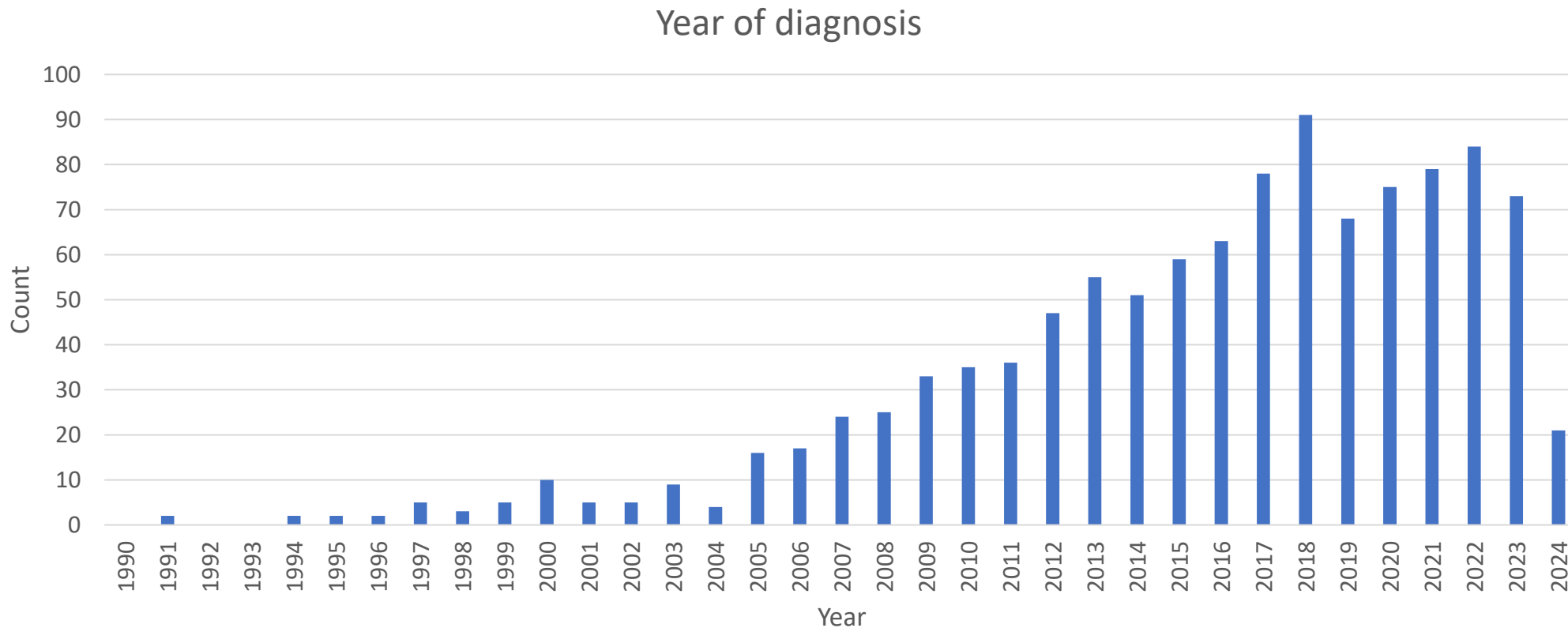


Family members also diagnosed with CLL/ SLL



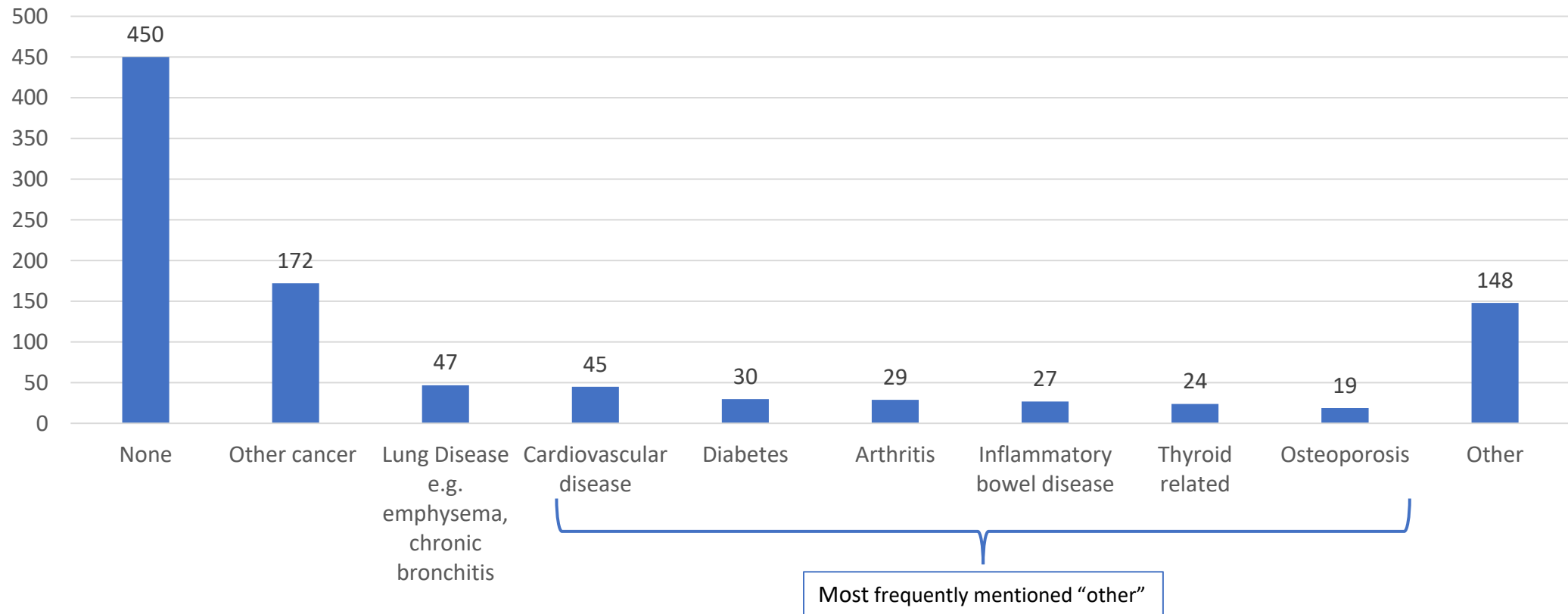
Year of diagnosis

Most respondents were diagnosed in the last 9 years, but people have been living with CLL / SLL for over 30 years.
Overall little difference seen between men and women in terms of year of diagnosis.



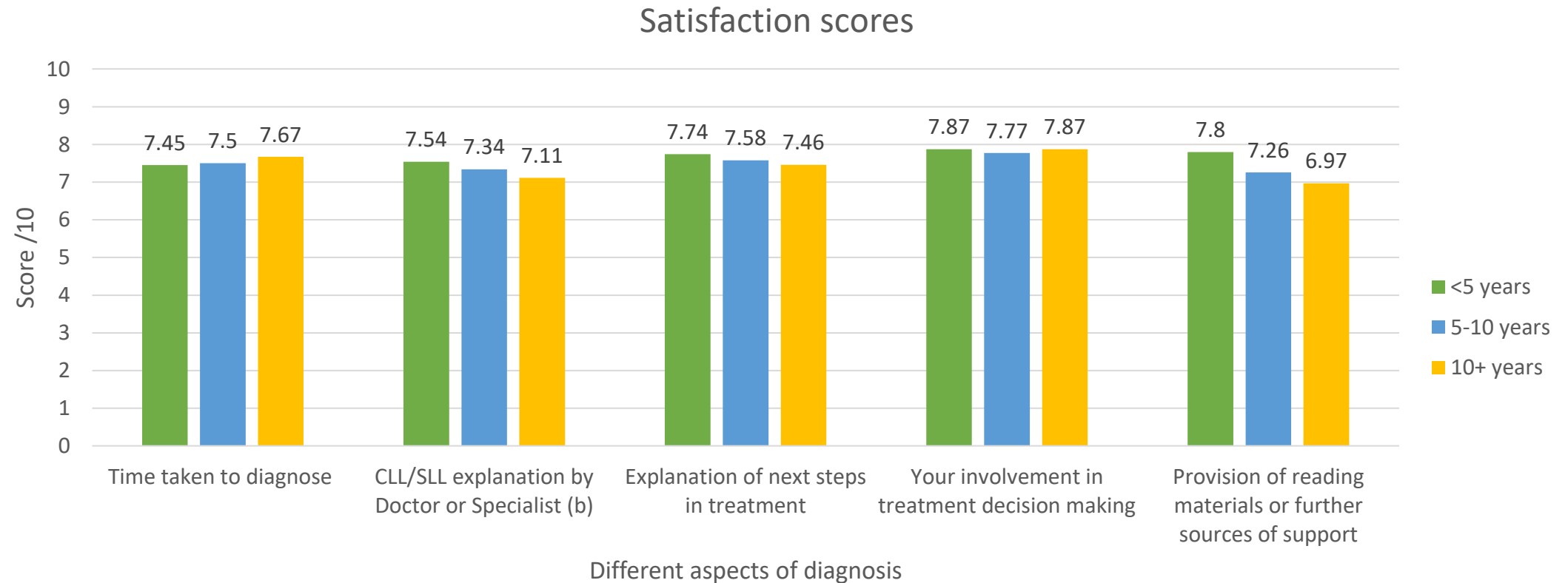
Co-morbidities

Nearly half the sample claim to have no comorbidities



Satisfaction at diagnosis

Relatively high satisfaction levels across different lengths of time since diagnosis'

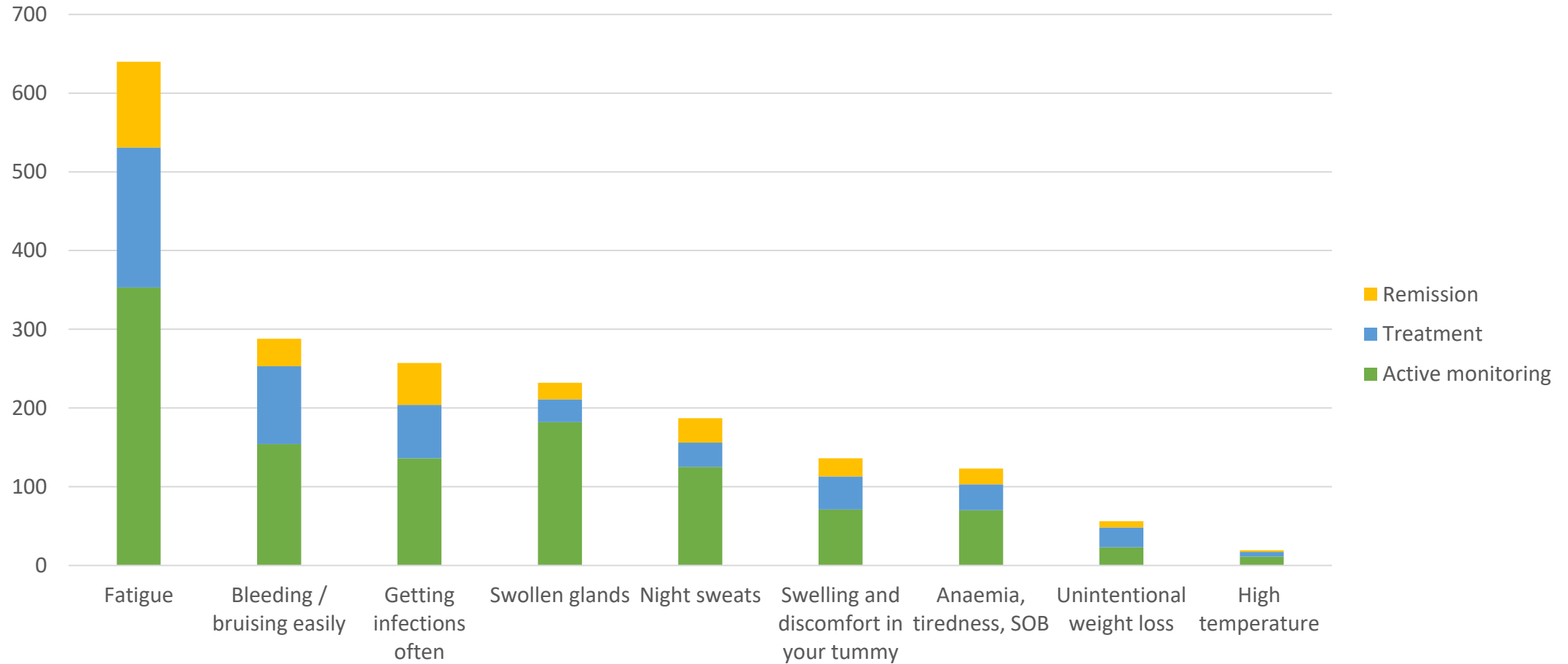


Current signs and symptoms

Fatigue was mentioned by over half the sample and more than any other symptom. These results are comparable to those in 2022

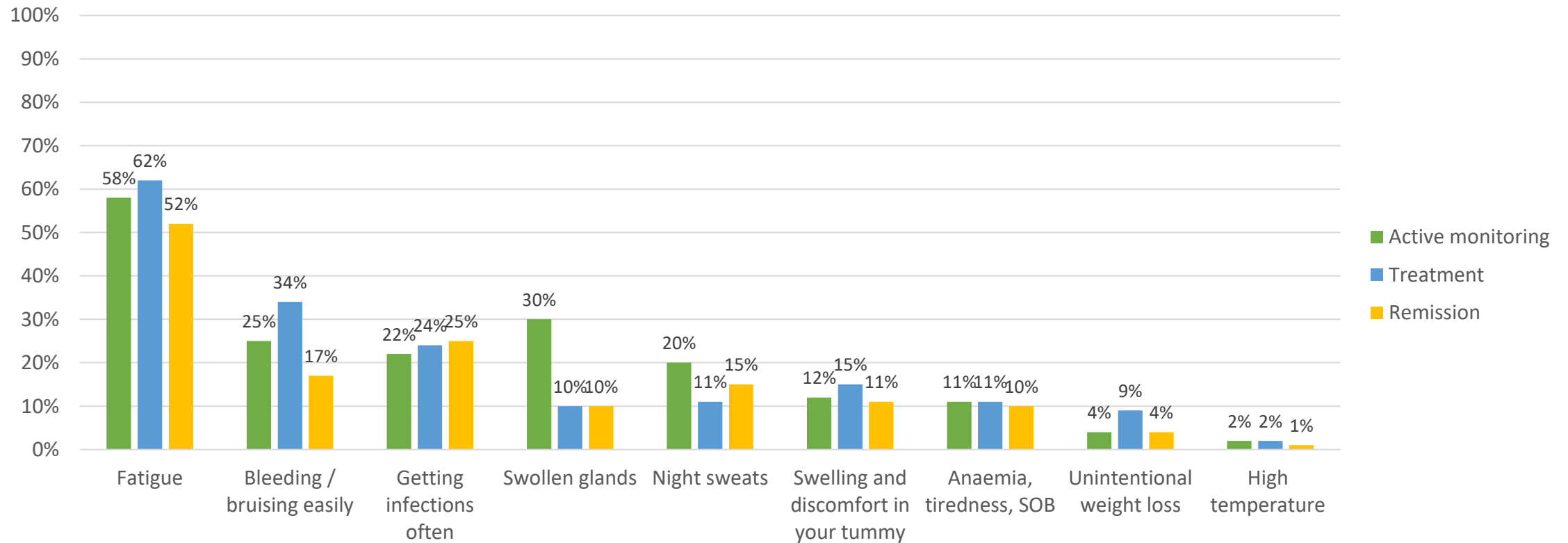


Current signs and symptoms by stage



Current signs and symptoms by stage

Fatigue, bleeding & bruising easily, and unintentional weight loss, impacted those on treatment significantly more
 Swollen glands are more common among those on active monitoring

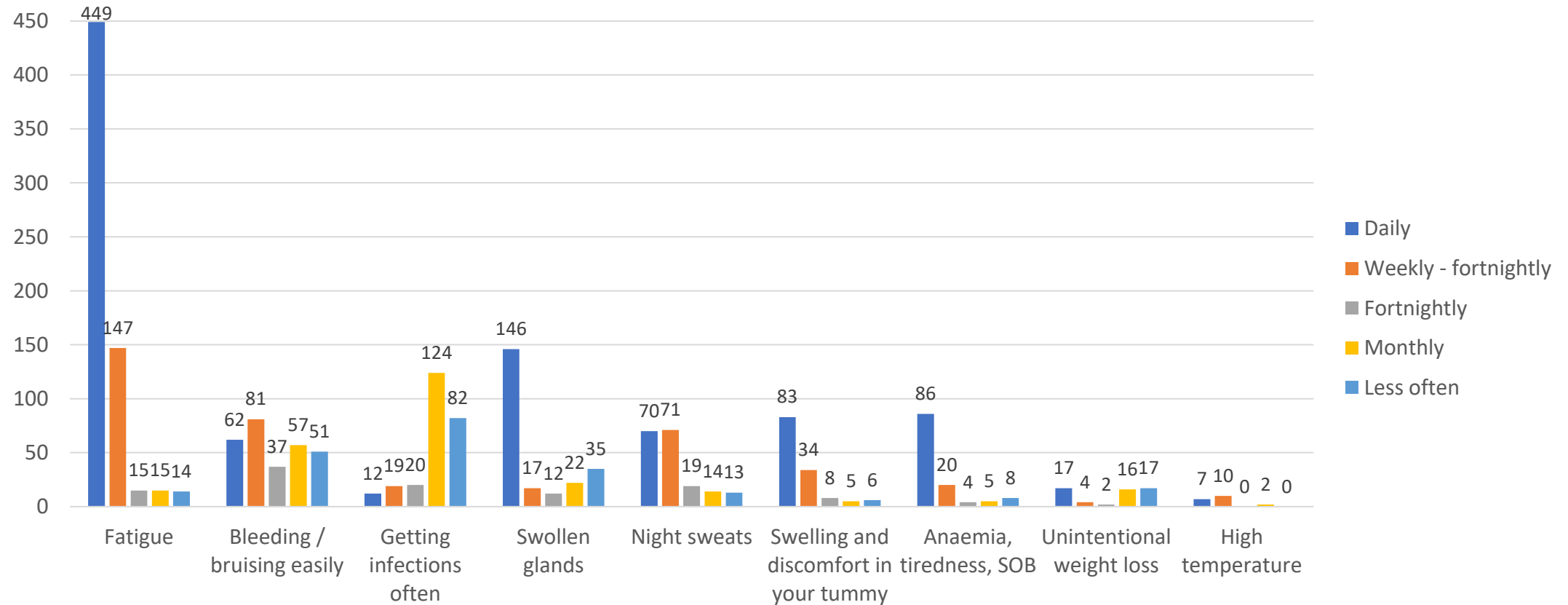


Q7a. Do you / does you family member have any current signs and symptoms of CLL or treatment? [Base n=1110]

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

Frequency of experiencing symptoms

The most frequent symptoms are fatigue, anaemia, swelling / discomfort in your tummy and swollen glands; 'getting infections often' occurs less frequently

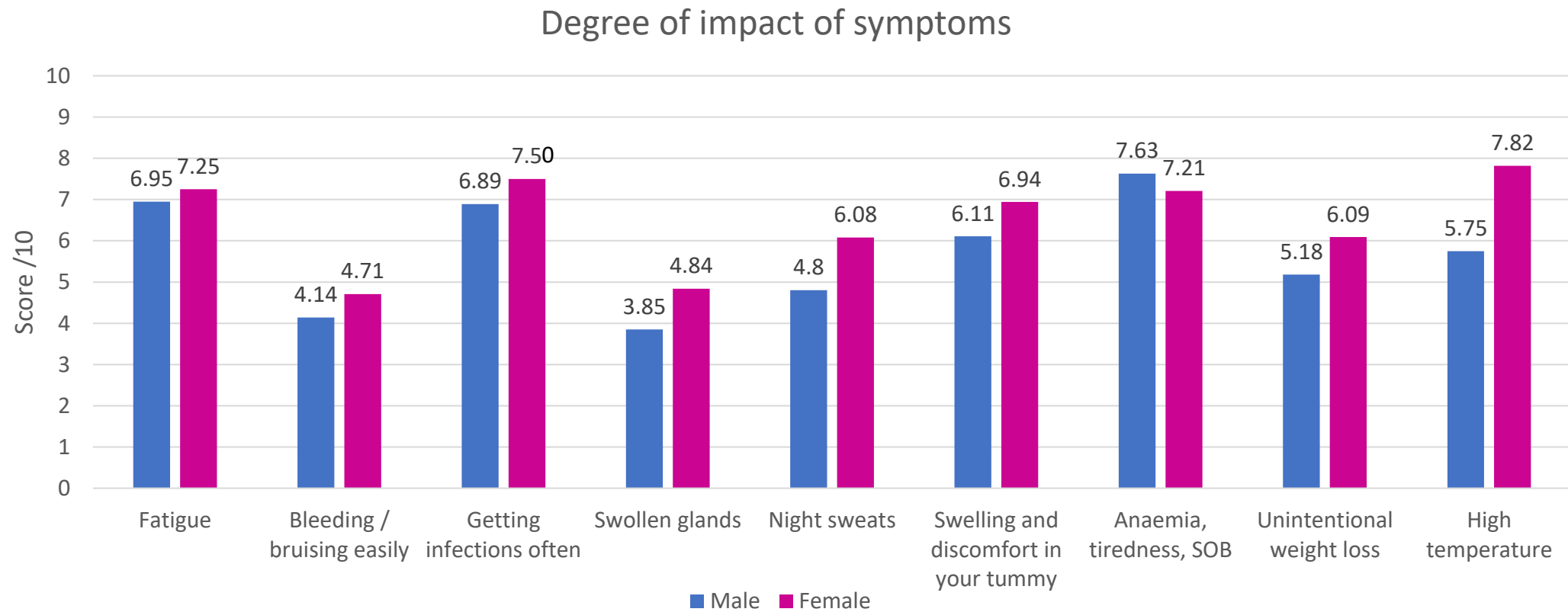


Q7a. Do you / does you family member have any current signs and symptoms of CLL or treatment? [Base n=1110]

Q7b: How often? [Base: Those with current symptoms]

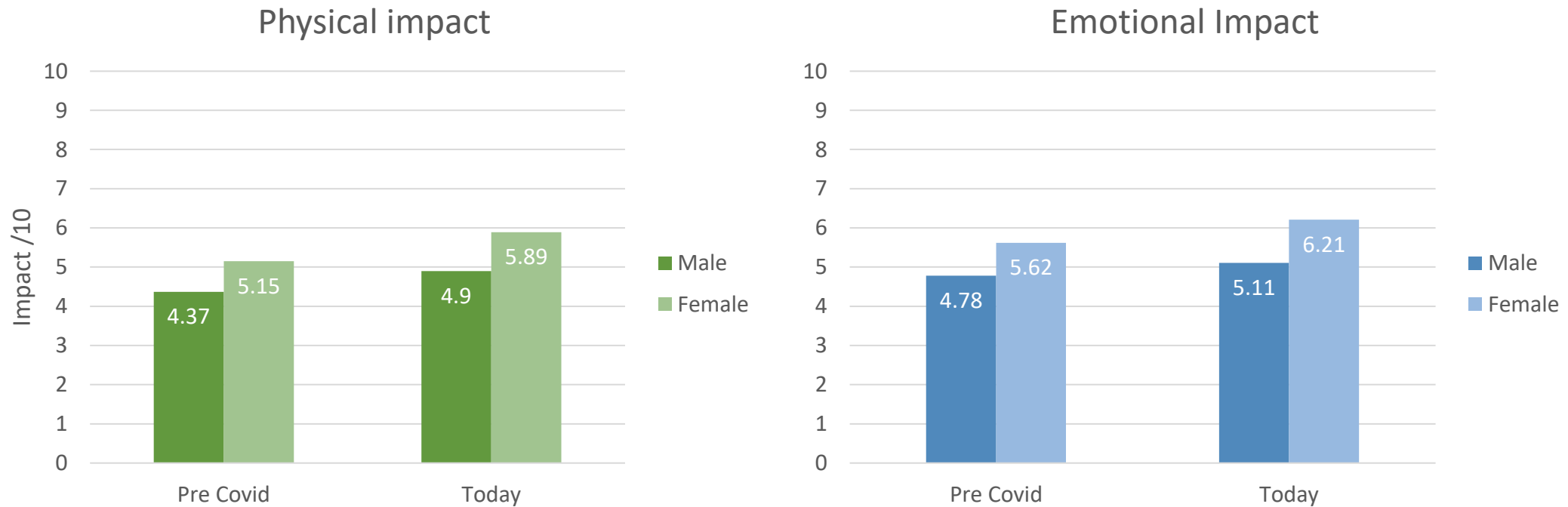
Impact of symptoms

In general women rated their symptoms as having more of an impact on their daily lives



Impact on quality of life – comparing pre pandemic with today

The pandemic appears to have raised both the physical and emotional impact of CLL / SLL on quality of life, particularly for women



Q8a. How much has your diagnosis of CLL/SLL or the diagnosis of your friend / family member affected your quality of life from a physical perspective? [Base pre/post n=777/997]

Q8b. How much has your diagnosis of CLL/SLL or the diagnosis of your friend / family member affected your quality of life from an emotional perspective? [Base pre/post n=777/997]

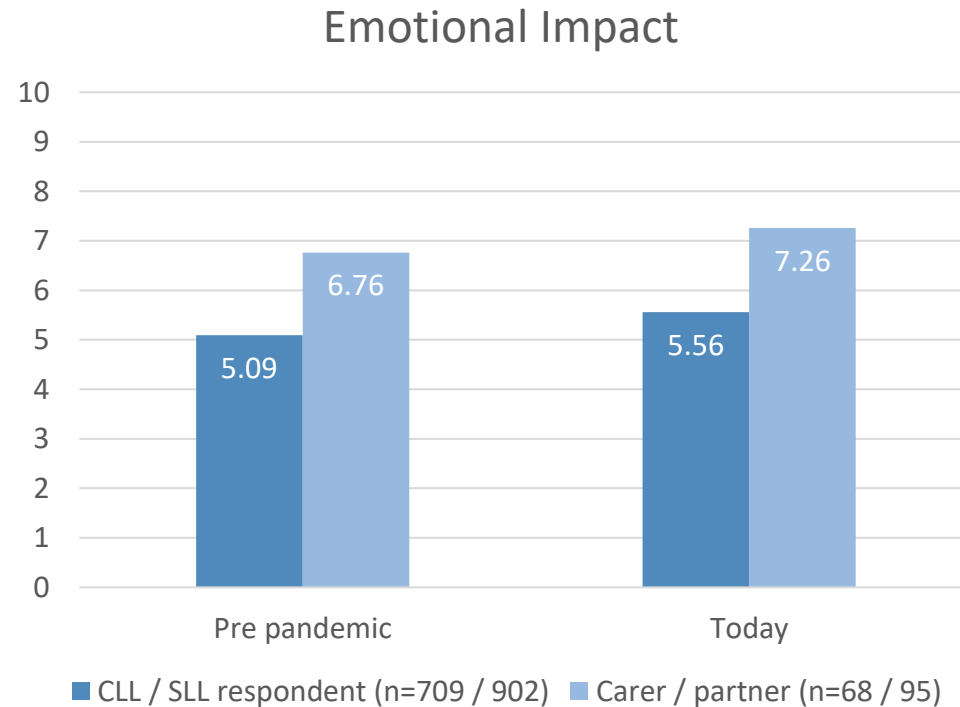
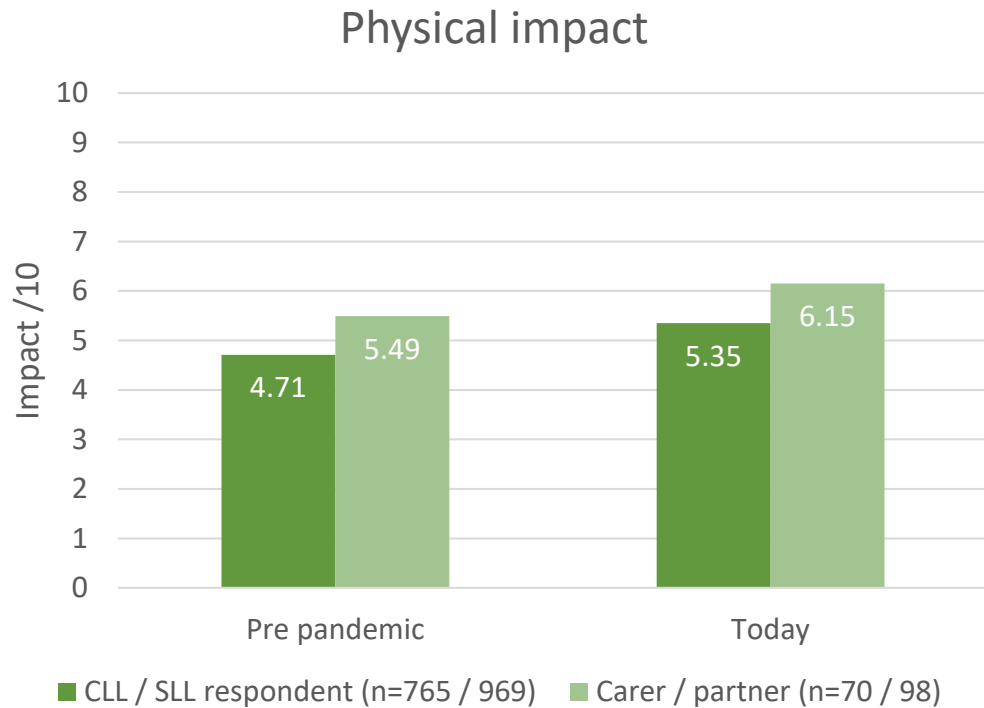
Impact on quality of life today across current situation

Respondents having treatment, rate the highest impact on their quality of life



Impact on quality of life - comparing patients with carers

Carers report a significantly greater impact on QOL than CLL / SLL patients

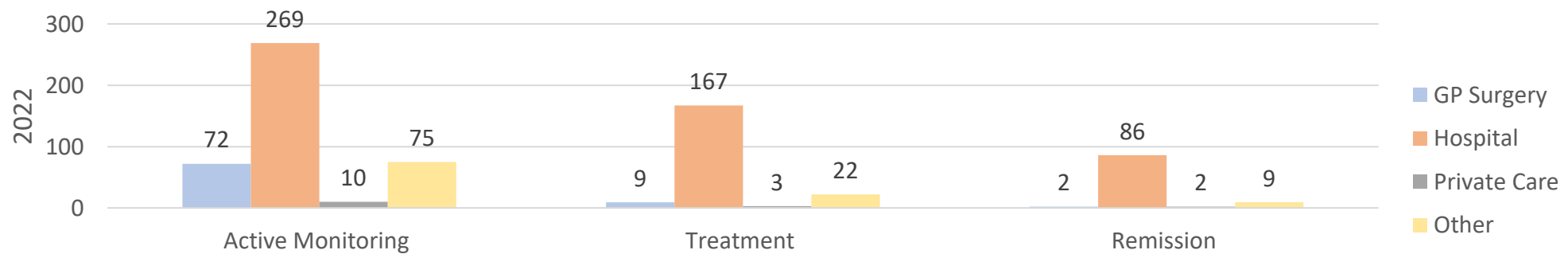
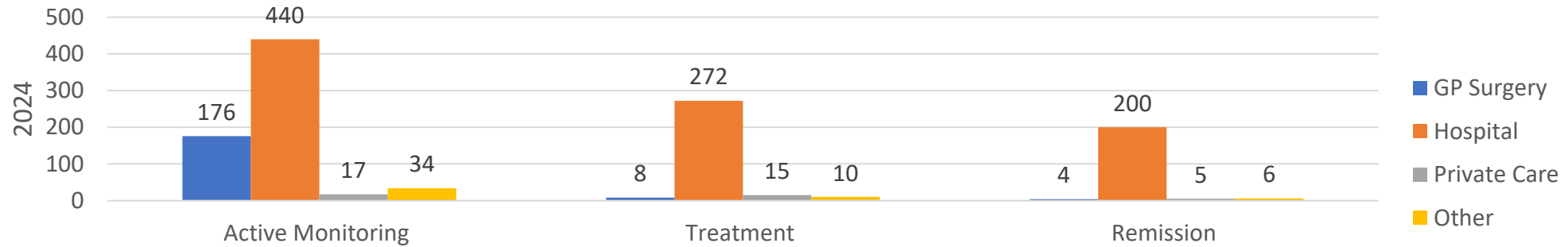


Q8a. How much has your diagnosis of CLL/SLL or the diagnosis of your friend / family member affected your quality of life from a physical perspective?

Q8b. How much has your diagnosis of CLL/SLL or the diagnosis of your friend / family member affected your quality of life from an emotional perspective?

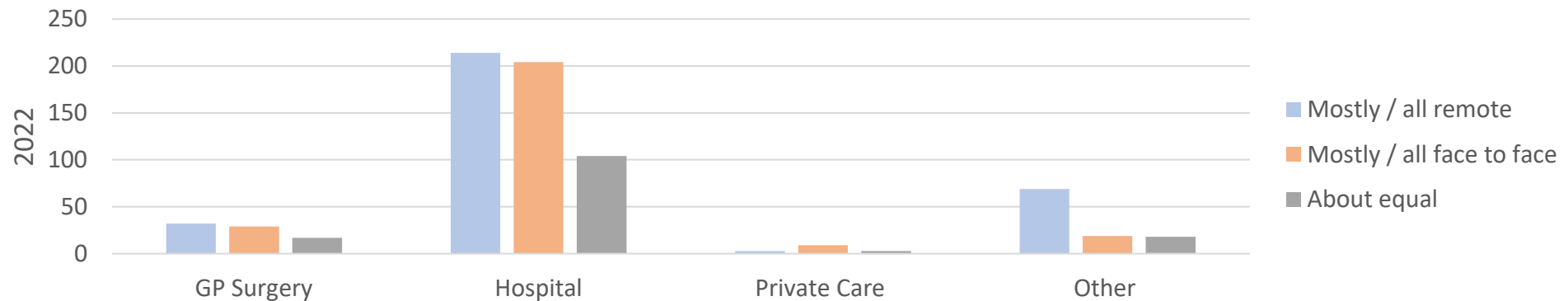
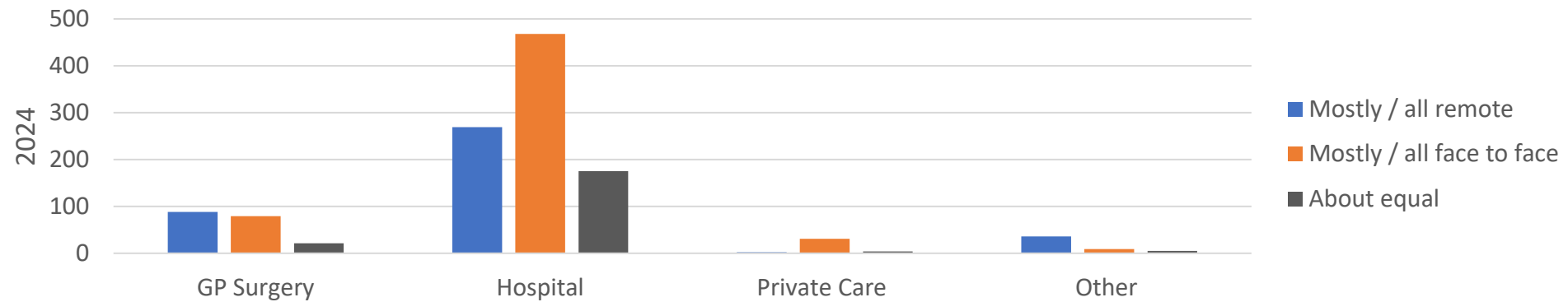
Sites of treatment

Location of management of CLL / SLL is similar to 2022



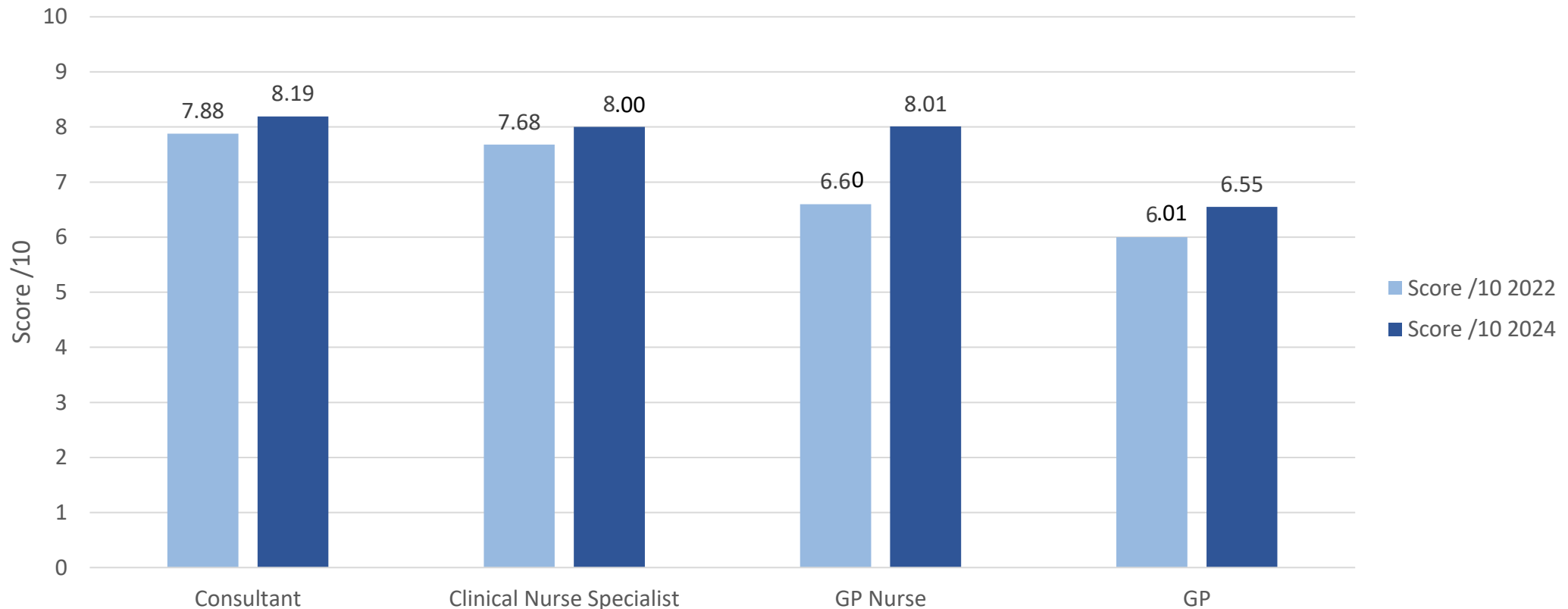
Consultation format

Consultations are now predominantly face to face



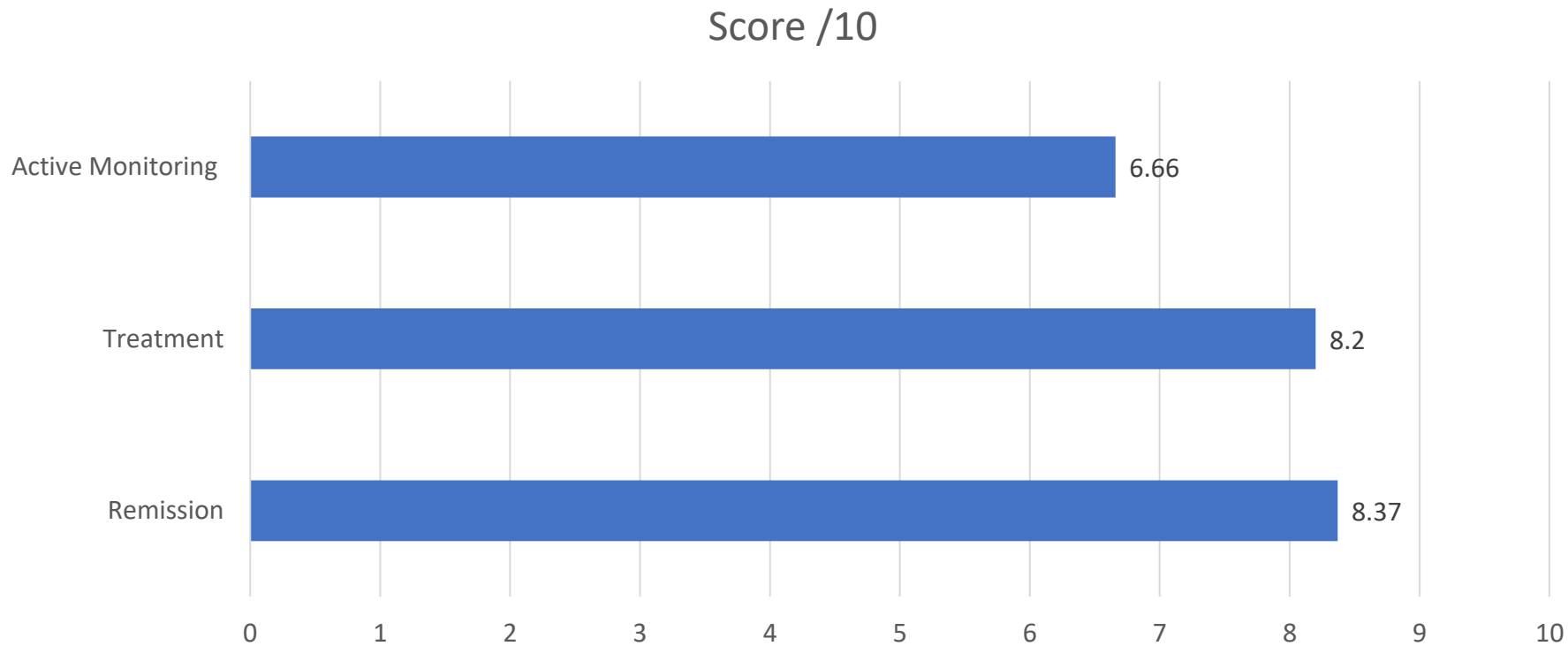
Satisfaction with clinical support

Scores in 2024 are better than in 2022



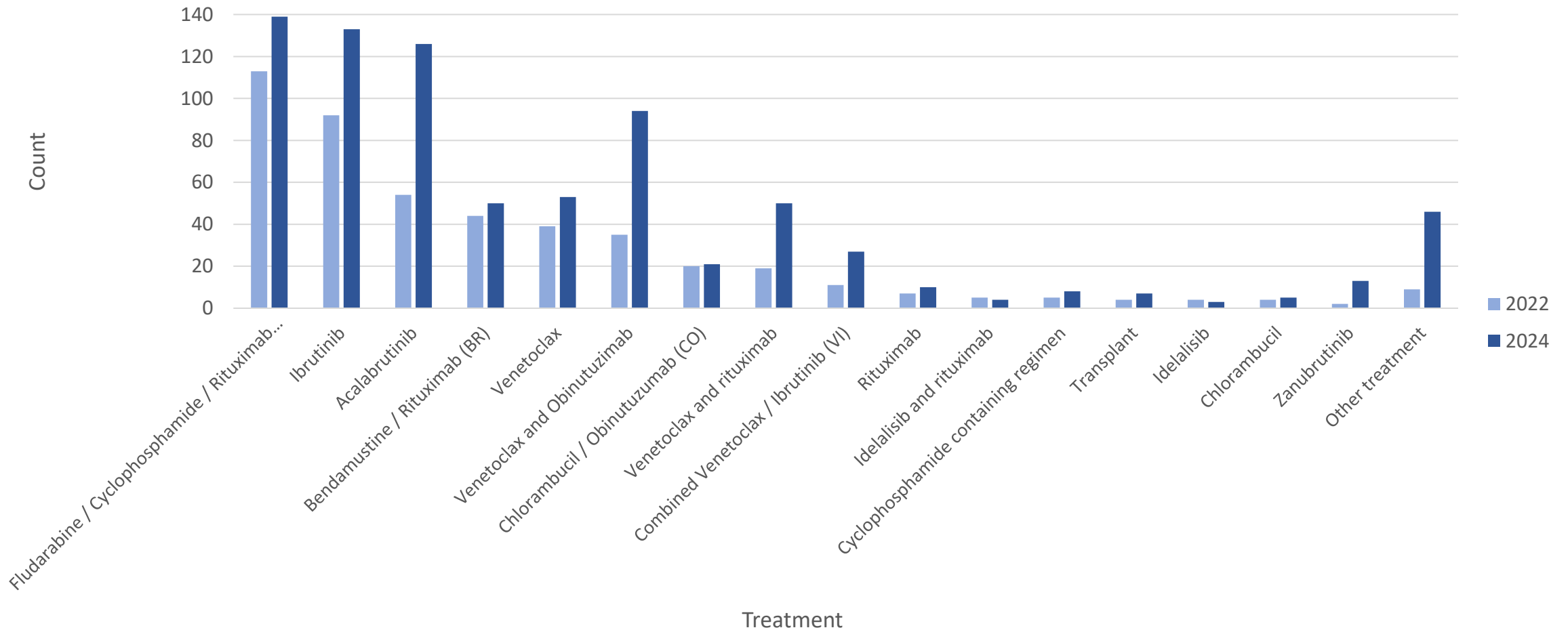
How well informed about treatment

Respondents on Active Monitoring feel less well informed about treatment



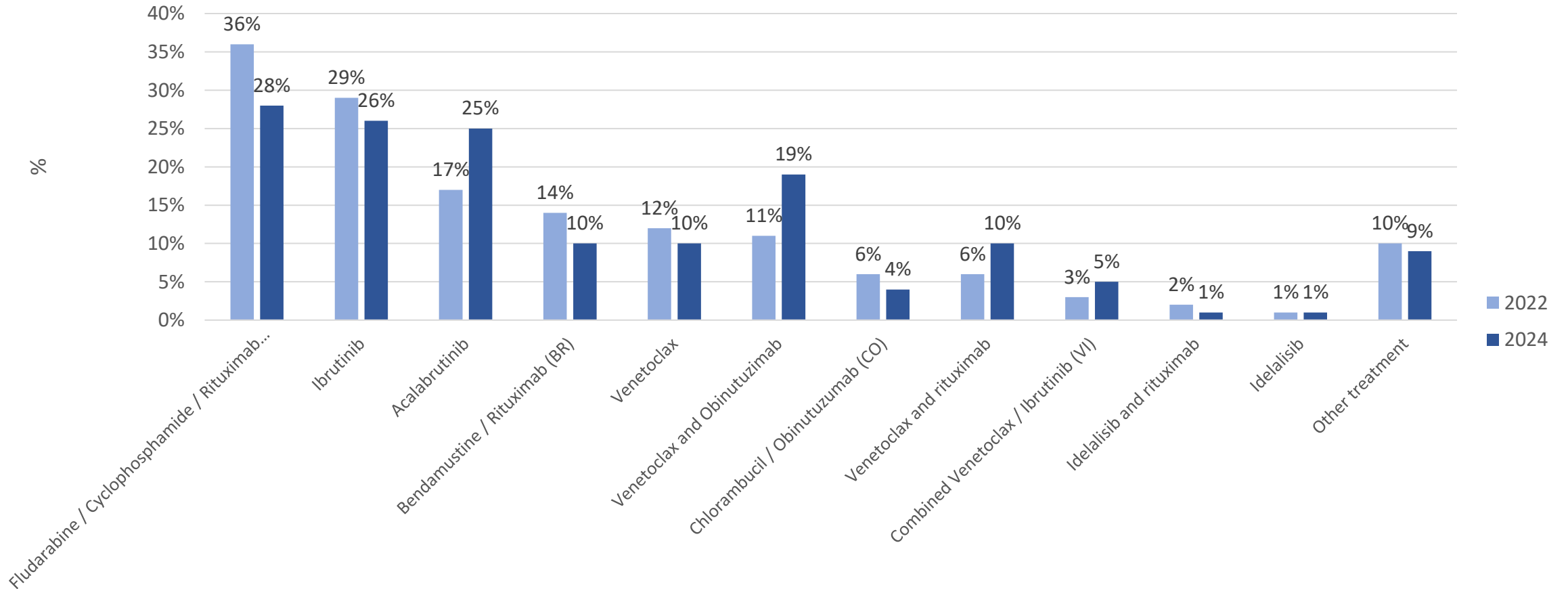
Treatments received

Cumulatively the most received treatment is still FCR.



Treatments received

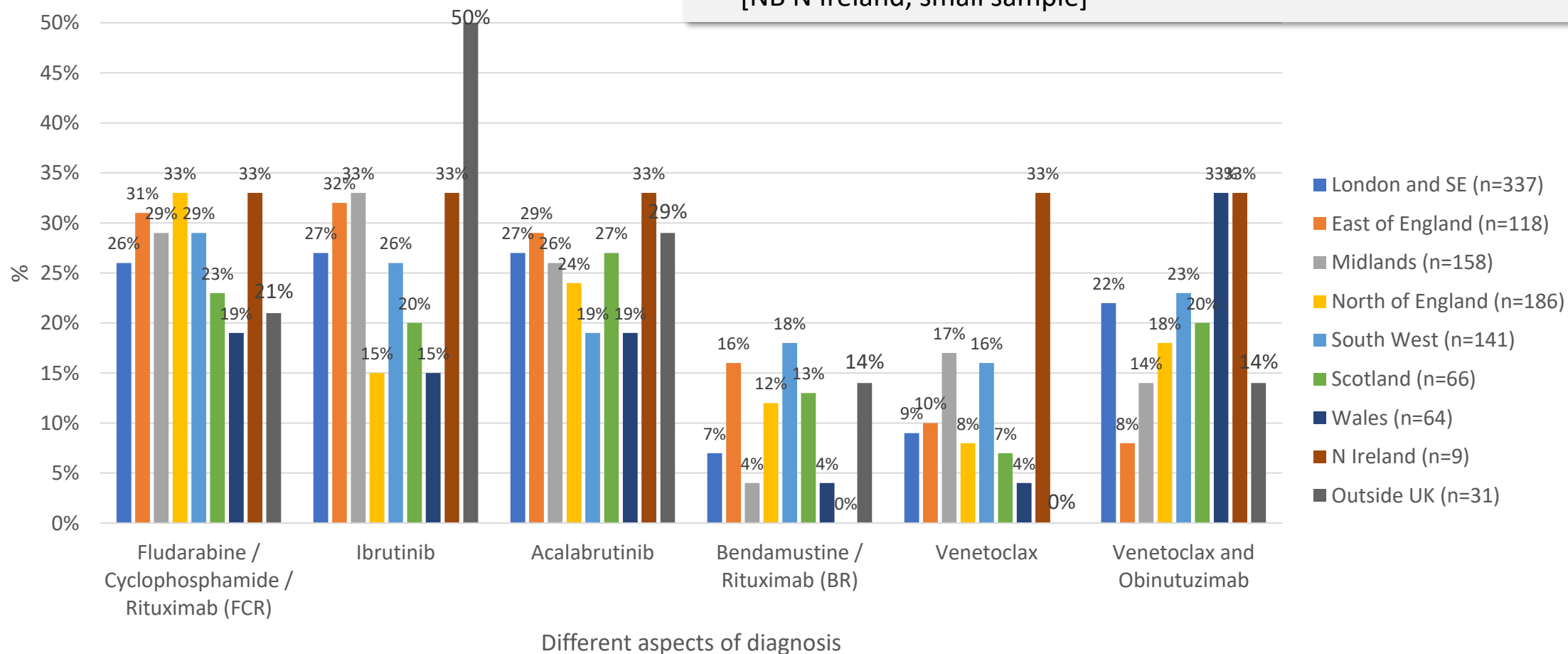
The largest increases in use from 2022 to 2024 can be seen in Acalabrutinib and Venetoclax + Obinutuzumab



Treatments received

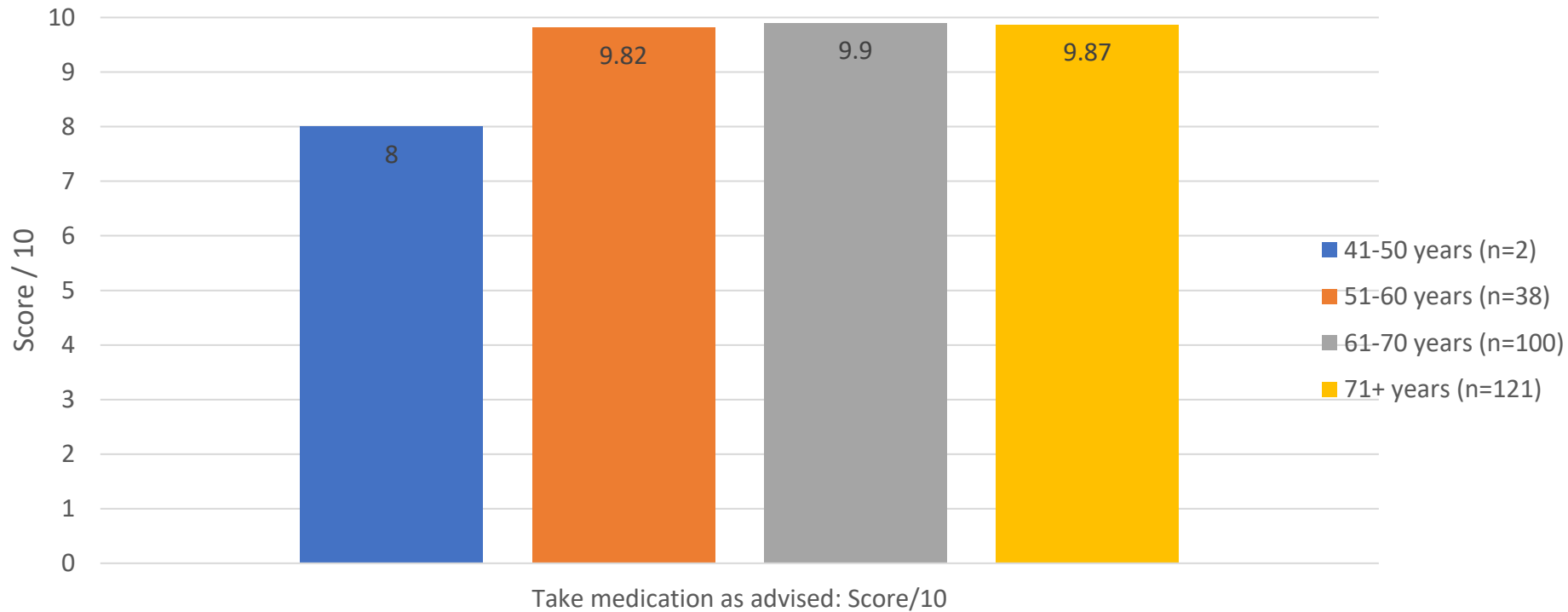
A few geographical differences can be seen

- Bendamustine / Rituximab is received more in East and SW England
- Ibrutinib is received least in the North of England
- [NB N Ireland, small sample]



Taking medication as advised

Medication is generally taken as advised across all respondents, with a small but significant drop in adherence in 41-50 year olds

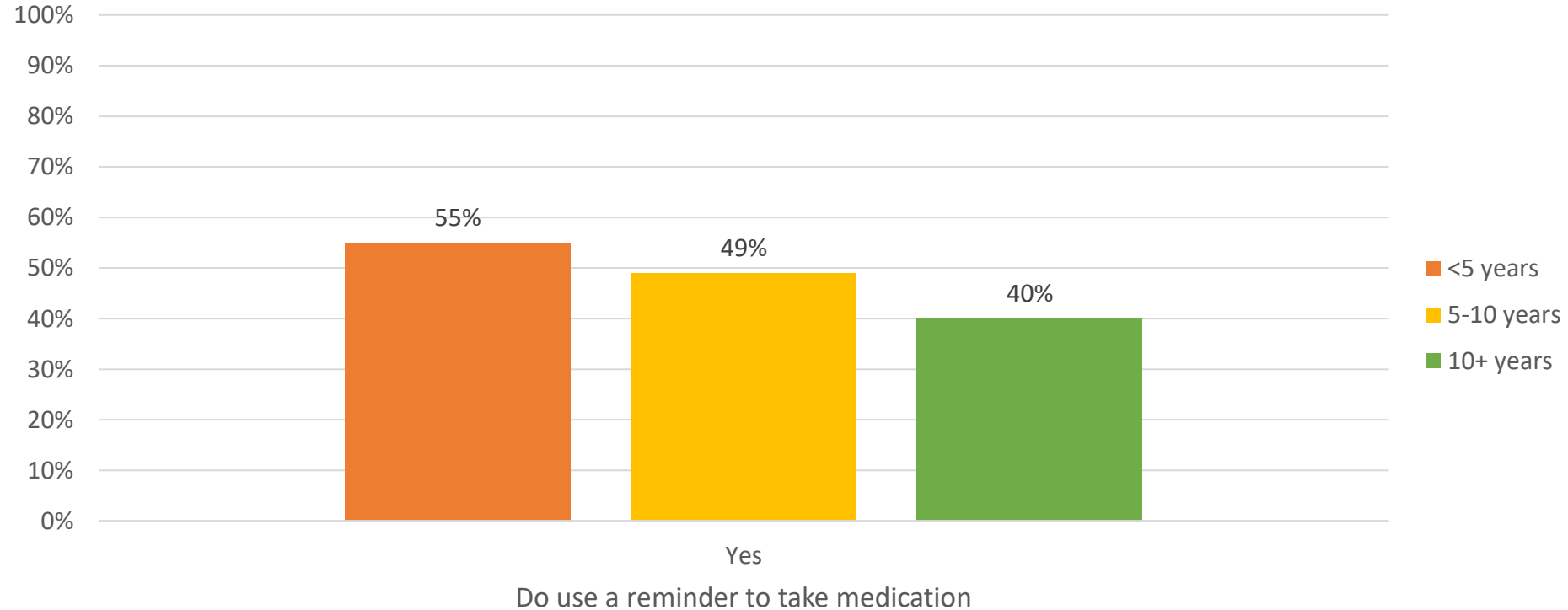


Q13a. To what extent do you take your/ your partner or family member take their/ does the person you're caring for take their/ does your friend take their CLL or SLL medication as advised?
[Base, those currently on treatment: n=289] 261

Q19. Into which of the following age groups do you fall? [Base n=1110]

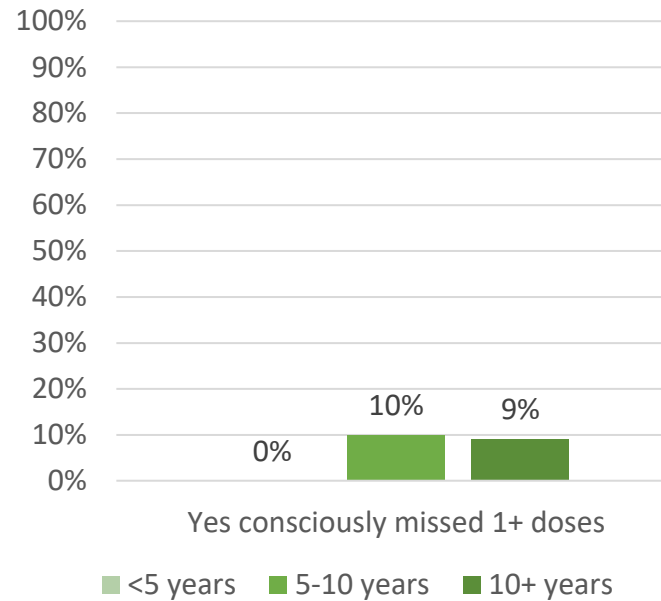
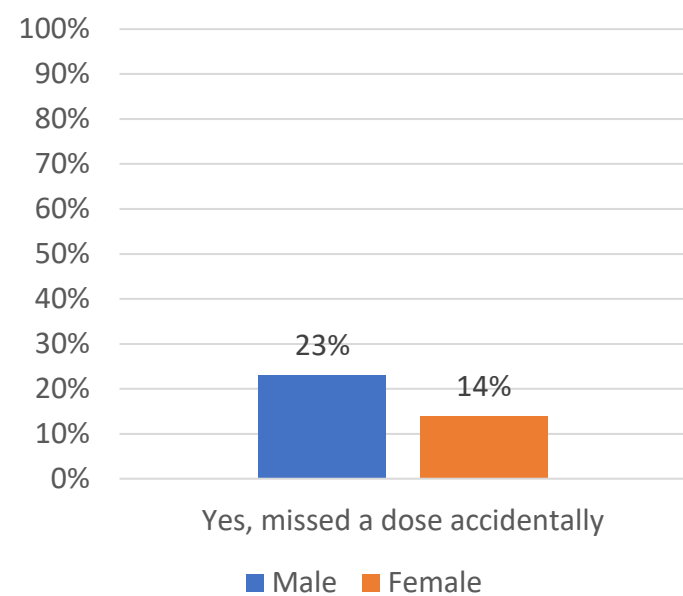
Using a reminder to take medication

Just under half overall, use a reminder to take their medication – this drops where the respondent was diagnosed over 10 years ago

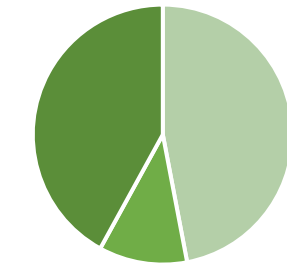


Missing doses in the last 4 weeks

Men are more likely to miss a dose accidentally than women; no one recently diagnosed consciously missed any doses in the past 4 weeks



Reasons for consciously missing a dose



- Adverse side effects
- Wanted a drug holiday
- Other

Q2. What year were you/ was your partner/ was the person you care for/ was your friend diagnosed with CLL/SLL? [Base n=1110]

Q20. What is your gender? [Base n=1110]

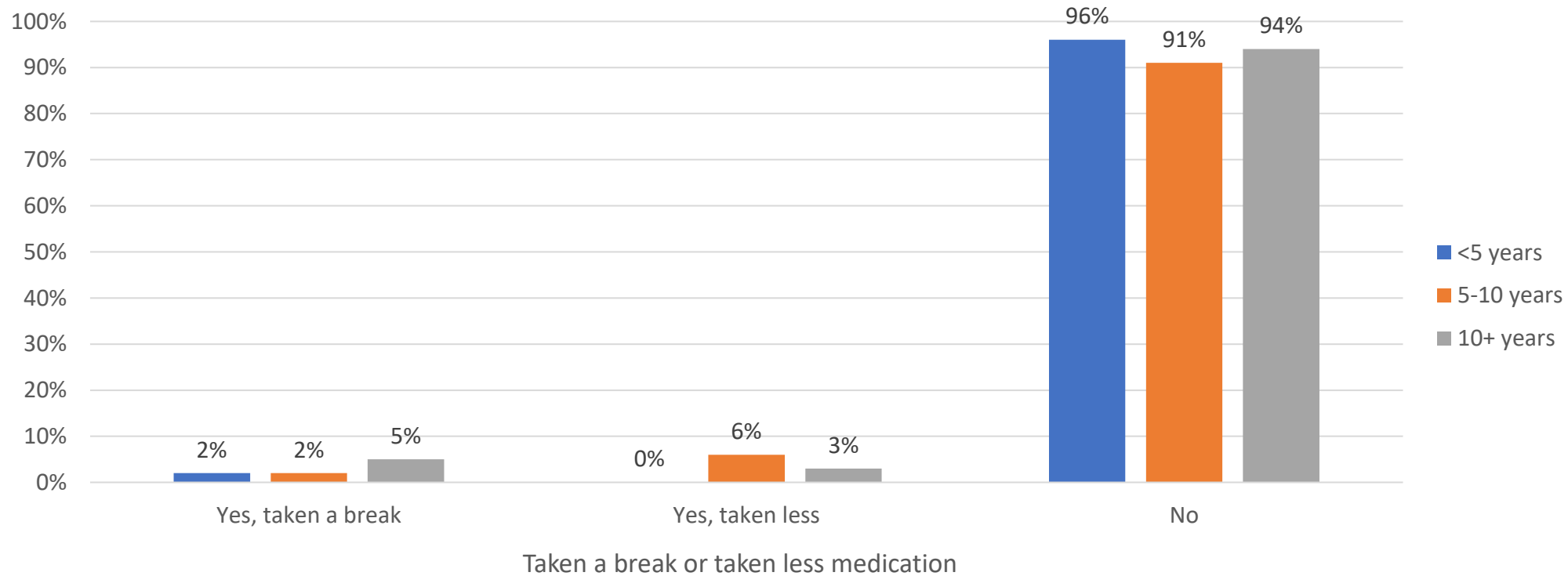
Q13c. In the last 4 weeks have you/ they missed one or more doses accidentally? [Base, those currently on treatment: n=289]

Q13d. In the last 4 weeks have you/ they consciously decided to miss one or more doses? [Base, those currently on treatment: n=289]

Q13d2. What was the reason? [Base, those currently on treatment: n=19]

Taking a break from medication

Only 9 of the 289 respondents taking medication had opted to take a lower dose (all diagnosed over 5 years ago), and 9 had taken a complete break at some point.



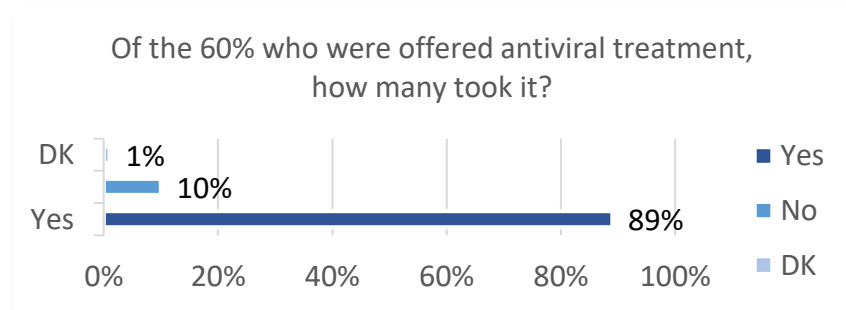
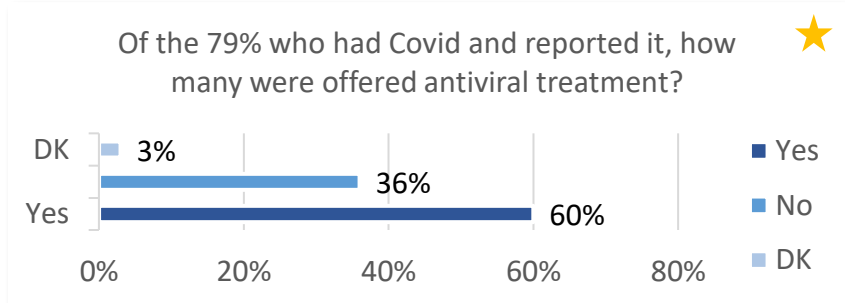
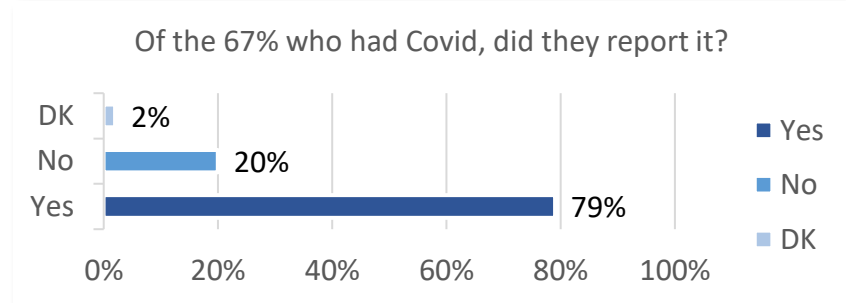
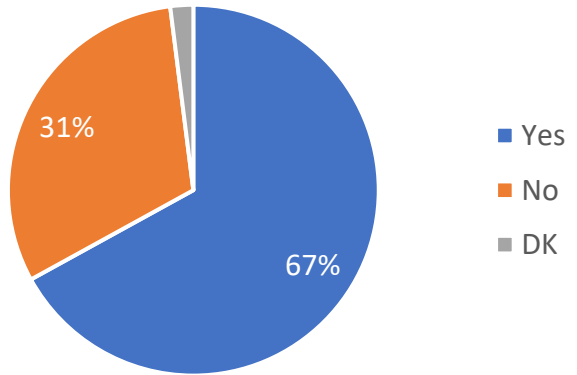
Q2. What year were you/ was your partner/ was the person you care for/ was your friend diagnosed with CLL/SLL? [Base n=1110]

Q13e. Have you/ they ever decided to take a break from your/ their medication, or to take less medication than prescribed without talking to your/ their doctor first? [Base, those currently on treatment: n=289]

Experience of having Covid

9/10 respondents have had a Covid vaccine – yet 2/3 of respondents had tested positive for Covid (twice as many as the sample in 2022)

Have you had Covid?



Q16. Have you had COVID-19? [Base n=1110] - **Respondents were asked to answer the remaining questions based on their most recent infection'.**

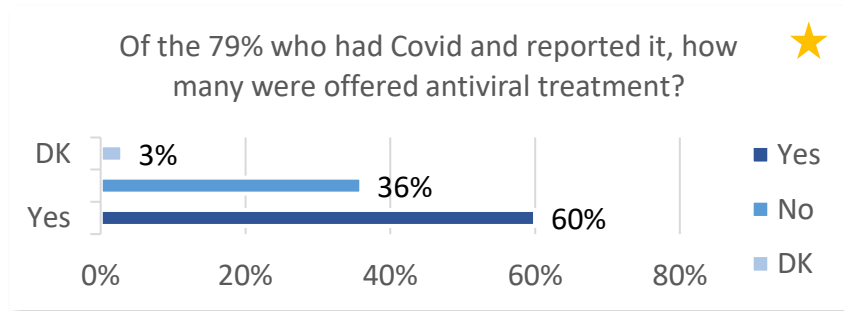
Q16c. Did you / they report it? (Base, those who had Covid, n=740]

Q16d. Were you/ they offered an antiviral course of treatment? (Base, those who had Covid & reported it, n=574]

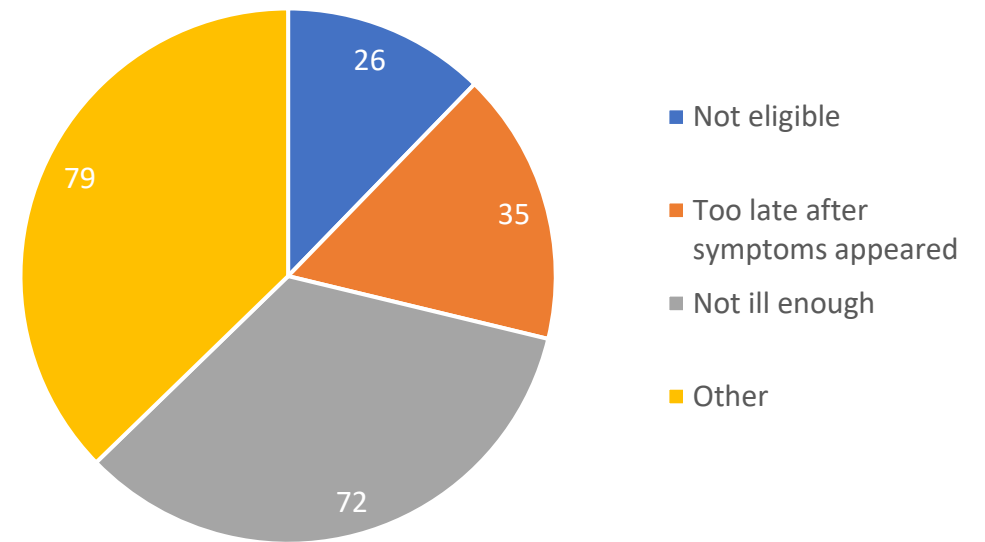
Q16e. Did you / they accept an antiviral course of treatment? (Base, those who were offered antiviral treatment, n=347]

Experience of having Covid

Respondents generally weren't offered antivirals if they weren't ill enough



Reasons for 36% not being offered antivirals



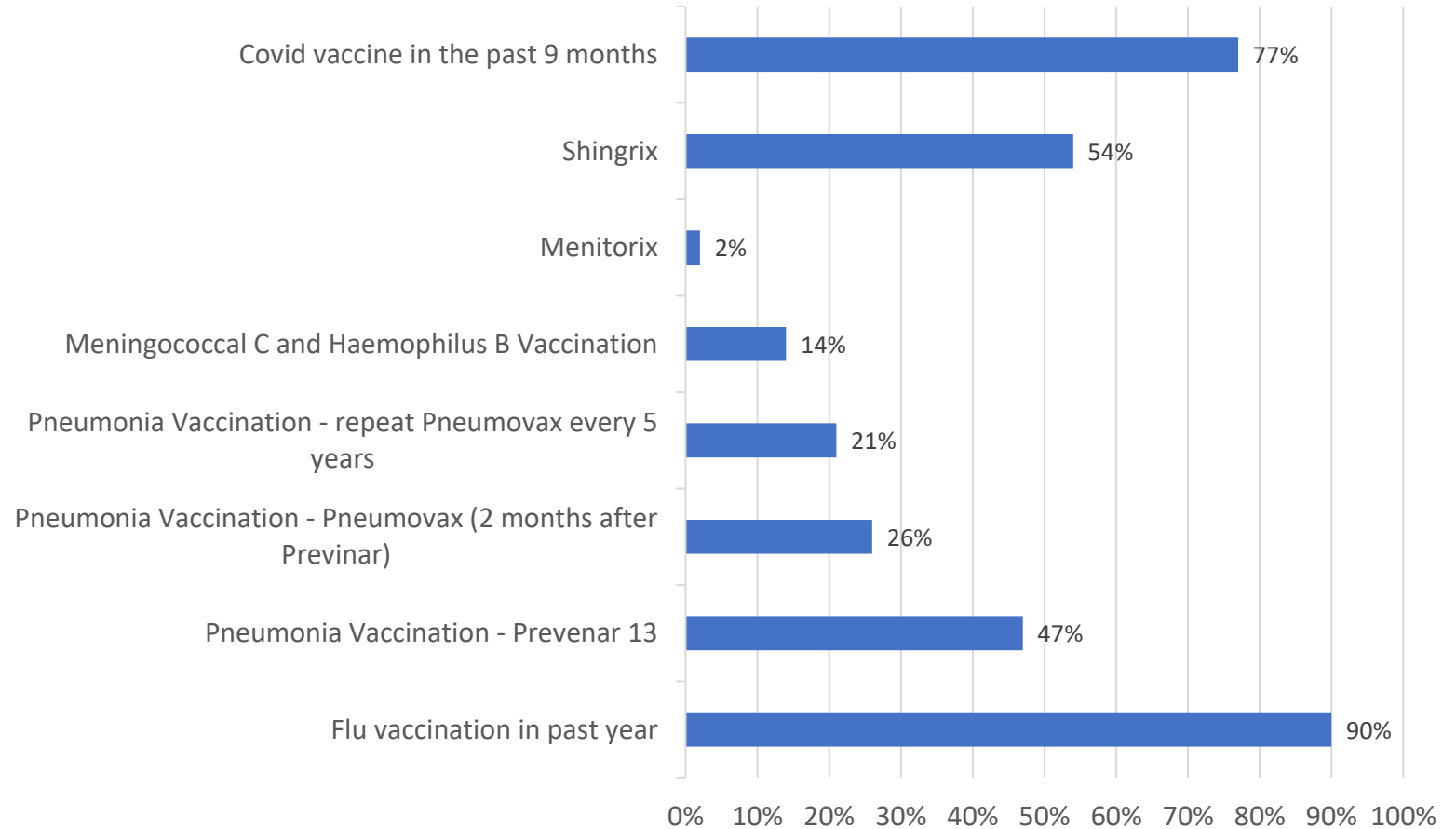
Q16d. Were you/ they offered an antiviral course of treatment? (Base, those who had Covid & reported it, n=574]
 Q16f. If you/ they were not offered antivirals, what reason(s) were you/ they given? [Base: Those who had COVID-19, and reported it, and were not offered an antiviral course of treatment, n=209]

Most respondents said they had received a Covid and a flu vaccine in the past 9 months



Mean score for how safe respondents feel about Covid vaccinations: **6.4/10**

Mean score for how well - informed respondents feel about which vaccinations are important: **7.1/10**



Q14. How well informed do you feel about which vaccines are important for CLL/SLL patients?

Q13. Which vaccinations have been received? . [Base n=1110]

Q14. How well informed do you feel about which vaccines are important for CLL/SLL patients? [Base n=1110]

Q15. How safe / protected do you feel since having the Covid vaccine? [Base n=1110]

CLL Support

Service awareness and access in 2024

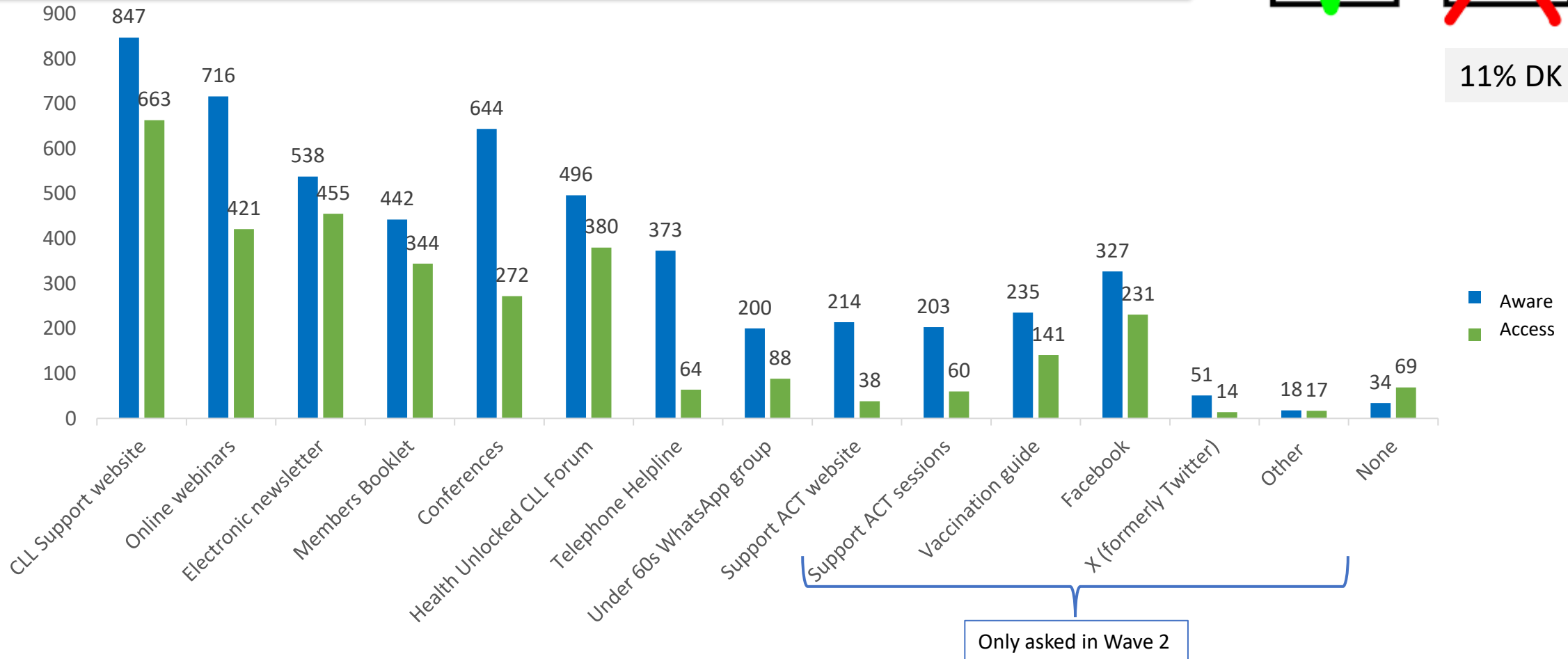
The lowest transfer of awareness to access was in conferences, the telephone helpline and Support ACT

83% respondents are members of CLL support

6% respondents are not members of CLL support

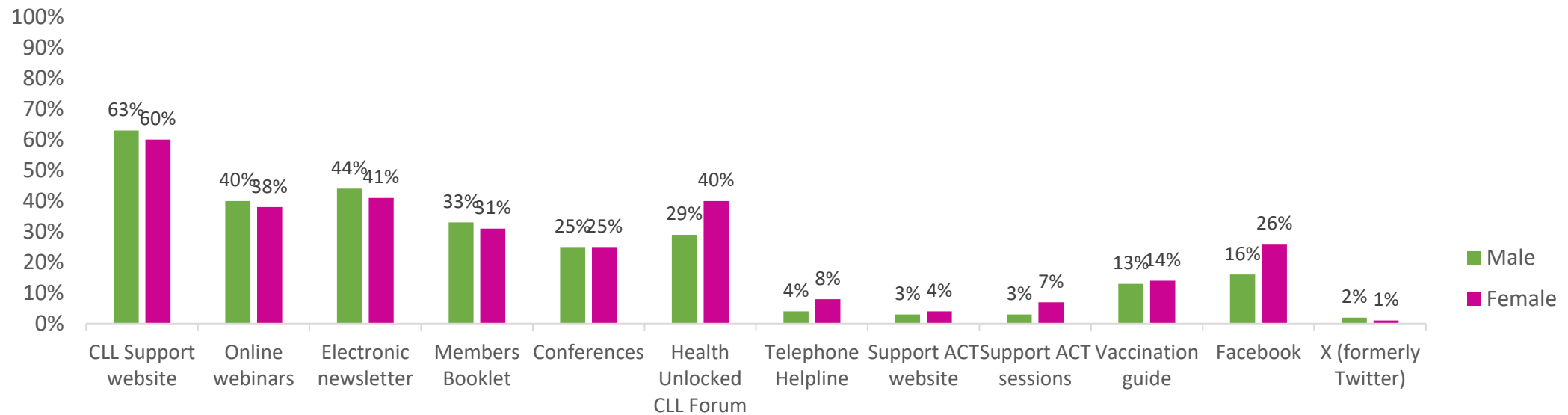


11% DK



Access to CLL Support services – gender

Awareness of services was comparable across men and women apart from Health Unlocked (greater awareness in women), however women were seen to access the services significantly more: Health Unlocked, Facebook, Under 60s WhatsApp, ACT Support Sessions, Telephone helpline



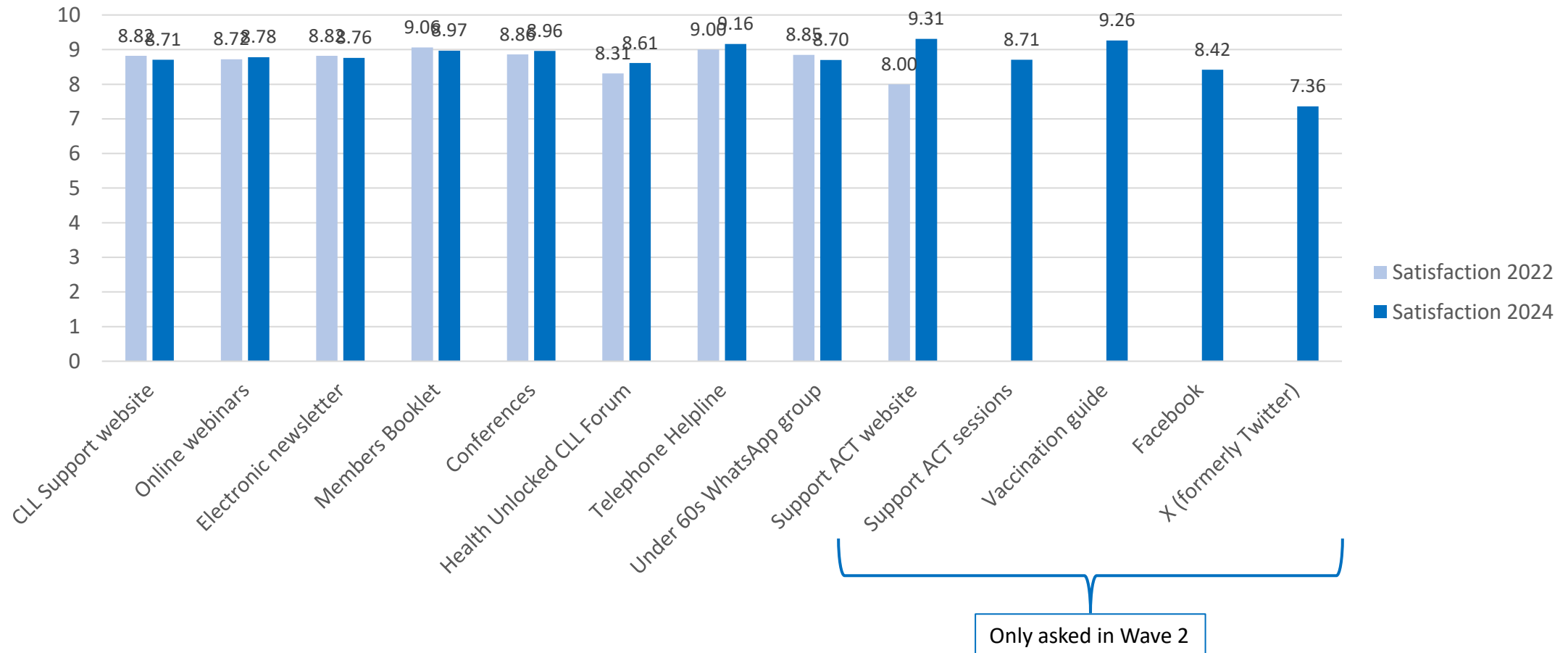
Services respondents have accessed

Only asked in Wave 2

Q20. What is your gender? [Base n=1110]
 Q17. As far as you know, are you a member of CLL Support? [Base n=1110]
 Q18b. And which of these CLL Support services have you accessed? [Those who are aware; Base n=1076]

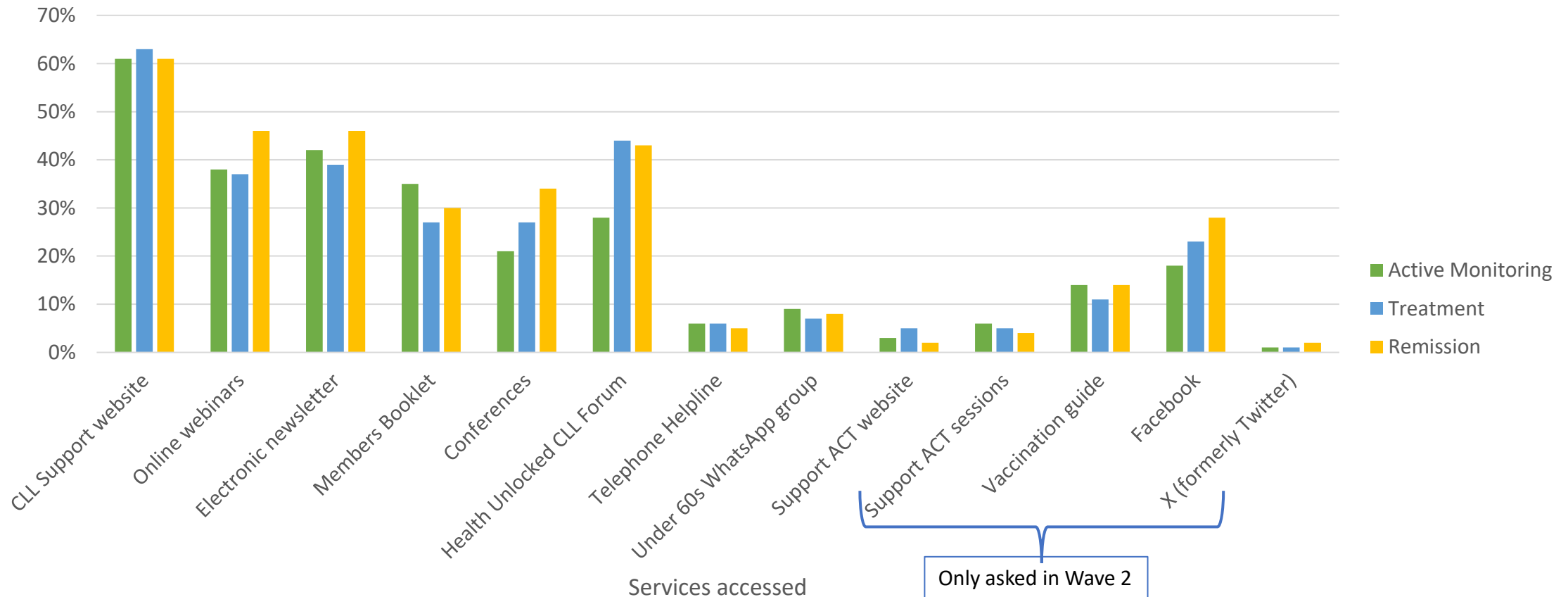
Level of satisfaction with CLL Support services

High levels of satisfaction were reported across all services offered, and with a notable increase in Support ACT website since 2022



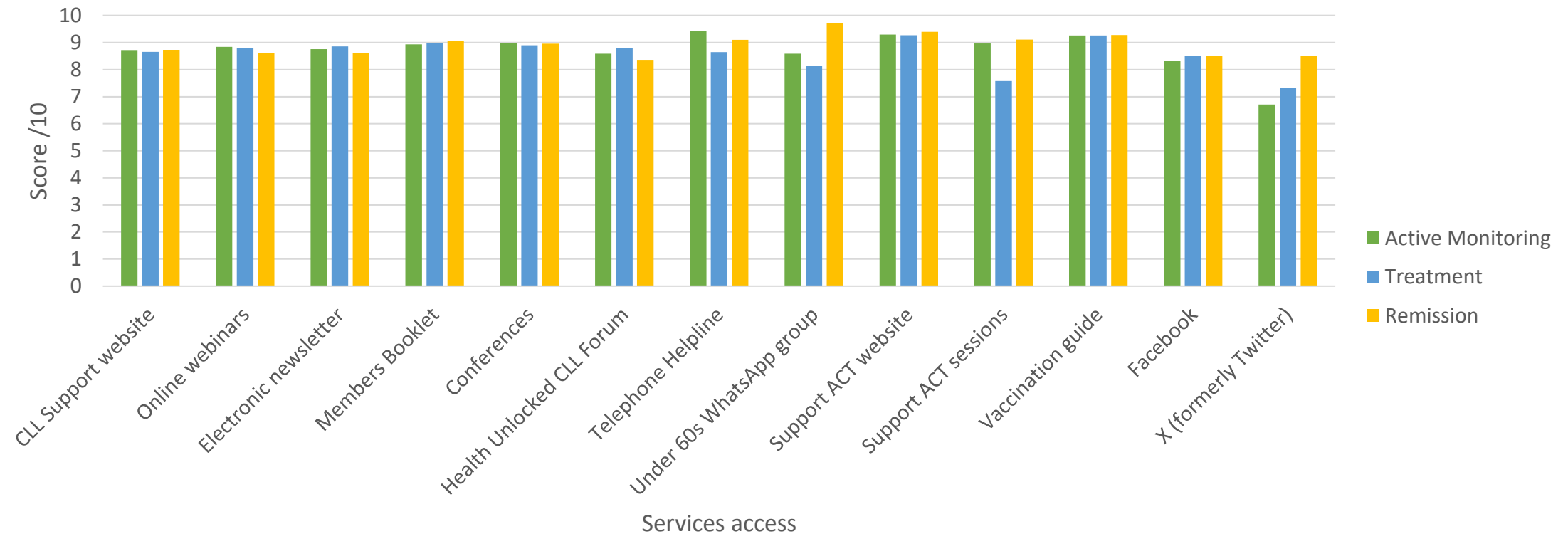
Services accessed – impact of CLL stage?

When the respondents are broken down by stage of CLL / SLL, those in remission appear to be more active in accessing Online webinars, electronic newsletters, conferences.



Level of satisfaction with CLL Support services – stage of treatment

Stage of treatment appeared to have little bearing on satisfaction with services except for those in remission who score more highly on the Under 60s WhatsApp group and Twitter. The telephone helpline also scored highly for those in remission and on active monitoring





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