



CLL Patient Voices Survey Final Report

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SUMMARY

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Objectives, sample & methodology

Project overview

OBJECTIVE

Understand the needs and treatment preferences of CLL patients, and ultimately challenge the chemo-immunotherapy treatment paradigm:

- What would patients prefer, and why
- What drives patients' treatment decisions
- What role do patients play in treatment decisions, and who influences decision making
- Where do patients get information about CLL

METHODOLOGY



10-minute online survey conducted August 2017 to March 2018



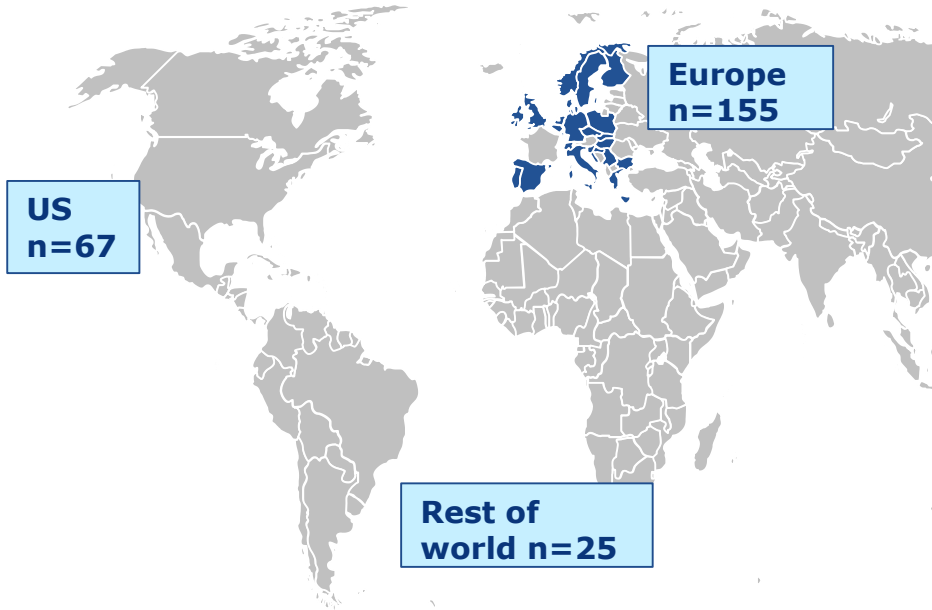
Promoted via CLL Patient Advocacy Groups and...



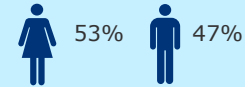
Social media

The survey was actively promoted in 24 EMEA countries, resulting in 155 EMEA participants and 247 worldwide

Launched in 24 countries across EMEA, plus US;
Respondents from other regions could also participate



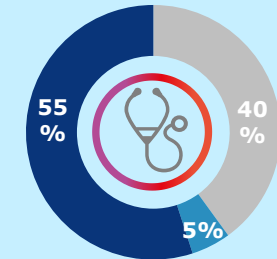
Gender:



Age:

63 years (median)
21% ≥70 years

Treatment status:

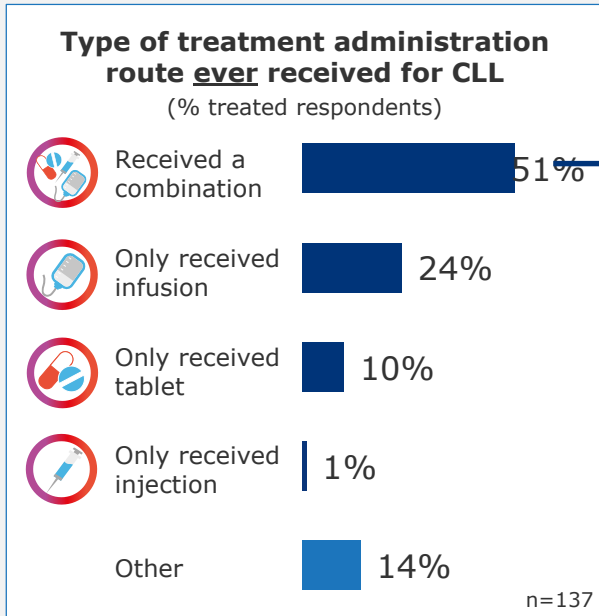


- Treatment naïve
- Due to start 1st treatment
- Received treatment

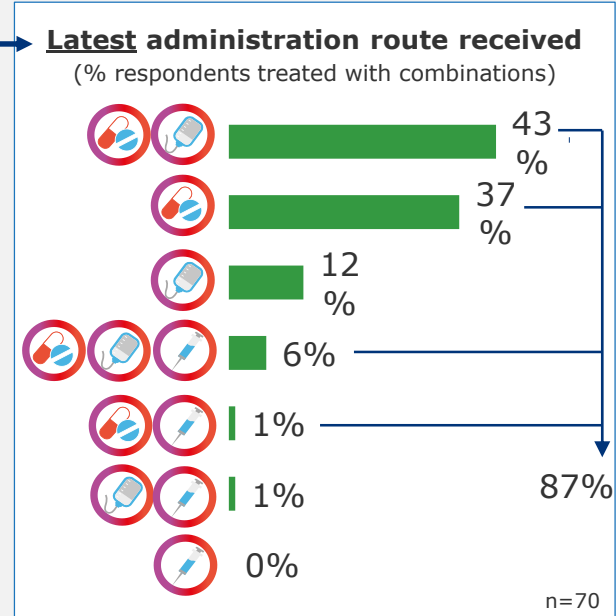
Findings

At least 54% of treated CLL patients have received tablet treatment

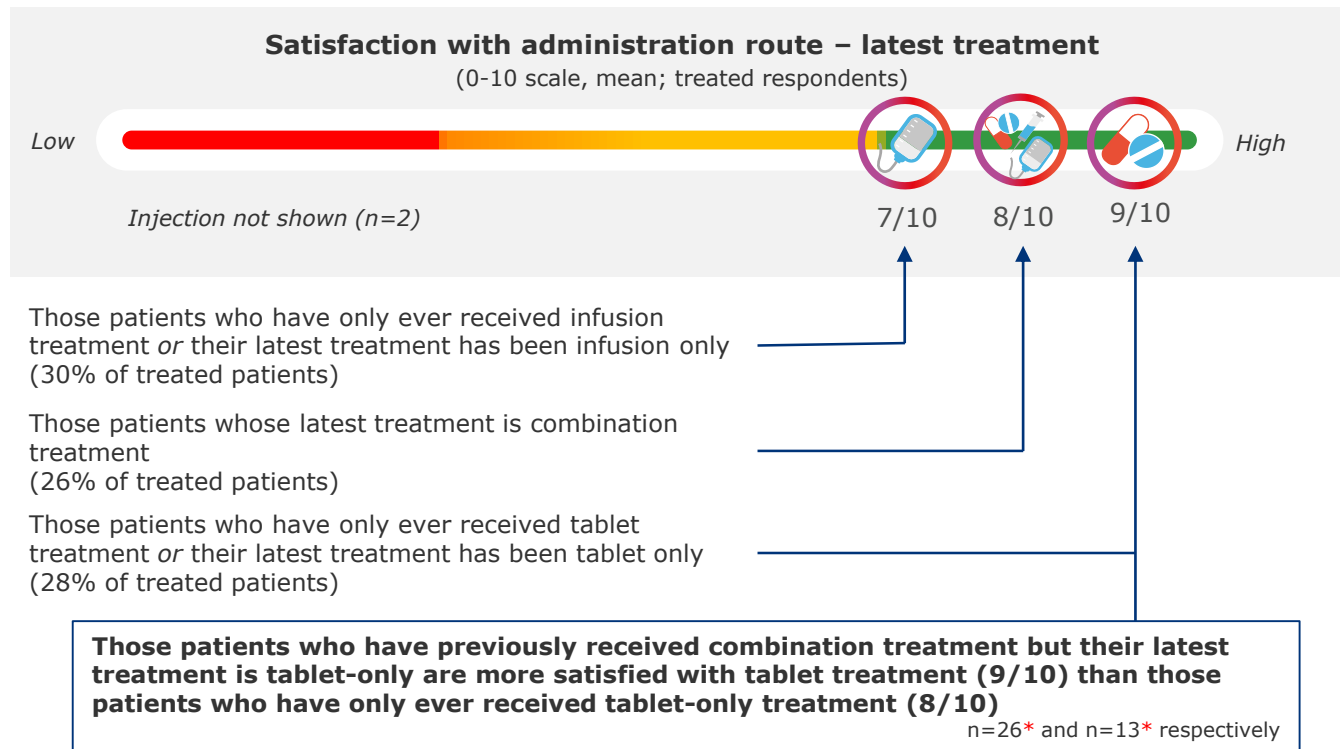
55% of CLL patients have received treatment
received treatment



45% of CLL patients have not received treatment



Patients on tablet-only are more satisfied than those using other administration routes



Base: Respondents who have received each treatment most recently (All treated n=137; Infusion only n=41; Tablet only n=39; Any combination n=36) - Q4a
See note section for details

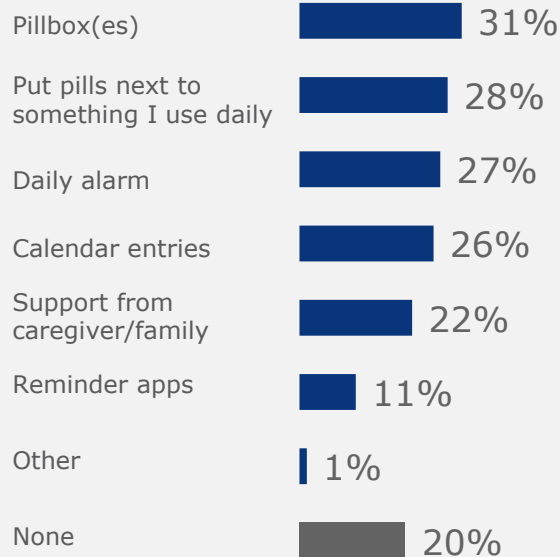
* CAUTION: LOW BASE

See Appendix for more information

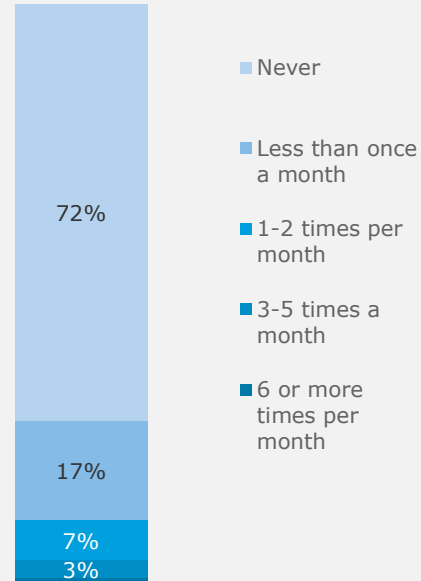
Patients on tablets use a variety of techniques to manage treatment adherence; 72% have never missed a dose



Techniques used for adherence
(% respondents treated with tablets)



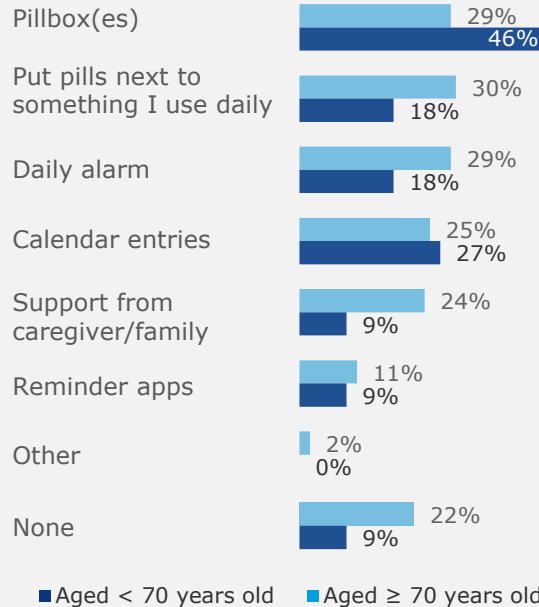
Frequency of missed doses
(% respondents treated with tablets)



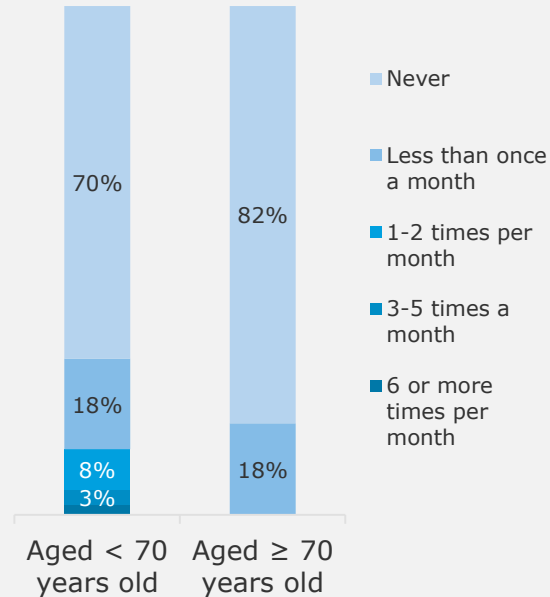
Older patients are more likely to use techniques to ensure they never miss a dose of tablet treatment



Techniques used for adherence
(% respondents treated with tablets)



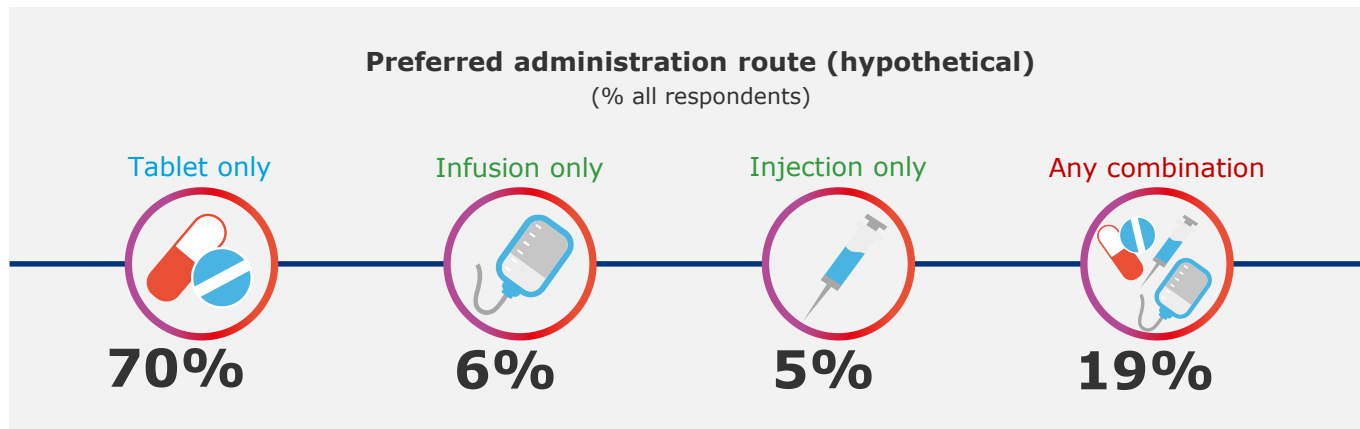
Frequency of missed doses
(% respondents treated with tablets)



Base: Respondents who have received tablets – either they have only ever received tablet treatment or their latest treatment includes tablets (< 70 years old n= 63; ≥ 70 years old n=11*) - Q9, Q10. See note section for details

* CAUTION: LOW BASE





Patients prefer tablet-only treatment



Base: All respondents (n=247) - Q4b
See note section for details





A preference for tablet-only treatment is true for both younger and older patients

Preferred administration route (hypothetical)
(% respondents)

	Tablet only 	Infusion only 	Injection only 	Combination 
n=194 Younger patients (<70 years)	69%	6%	5%	20%
n=53 Older patients (≥70 years)	73%	4%	6%	17%

A preference for tablet-only treatment is true even for those not receiving tablet treatment

Preferred administration route (hypothetical)
(% respondents)

		Tablet only 	Infusion only 	Injection only 	Combination 
n=247	All respondents	70%	6%	5%	19%
n=137*	Patients who have been treated	71%	7%	4%	18%
n=74	Patients whose latest treatment involved tablet	73%	8%	3%	16%
n=44	Patients whose latest treatment did not involve tablet	64%	9%	5%	23%
n=98	Treatment naïve patients	67%	3%	7%	23%

*Includes patients who stated their treatment as 'Other'

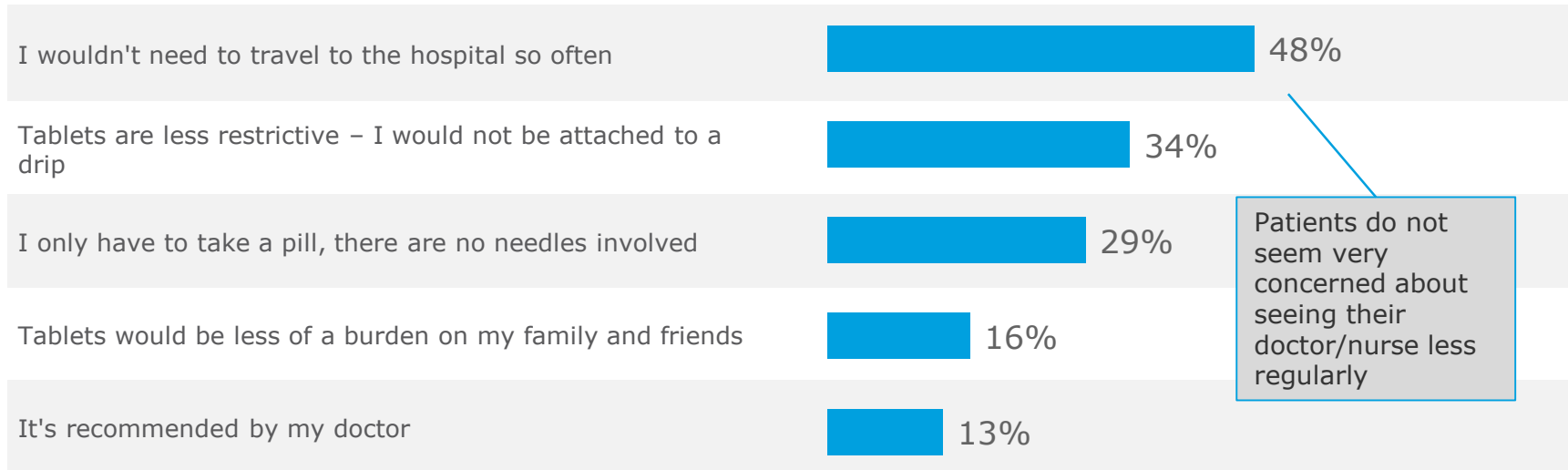
The freedom offered by tablet treatment is the primary driver for patients' preference....

 **70%**

Key reasons for hypothetical preference: **tablet only**

(% respondents who would prefer tablet-only treatment)

Respondents selected their Top 2 reasons



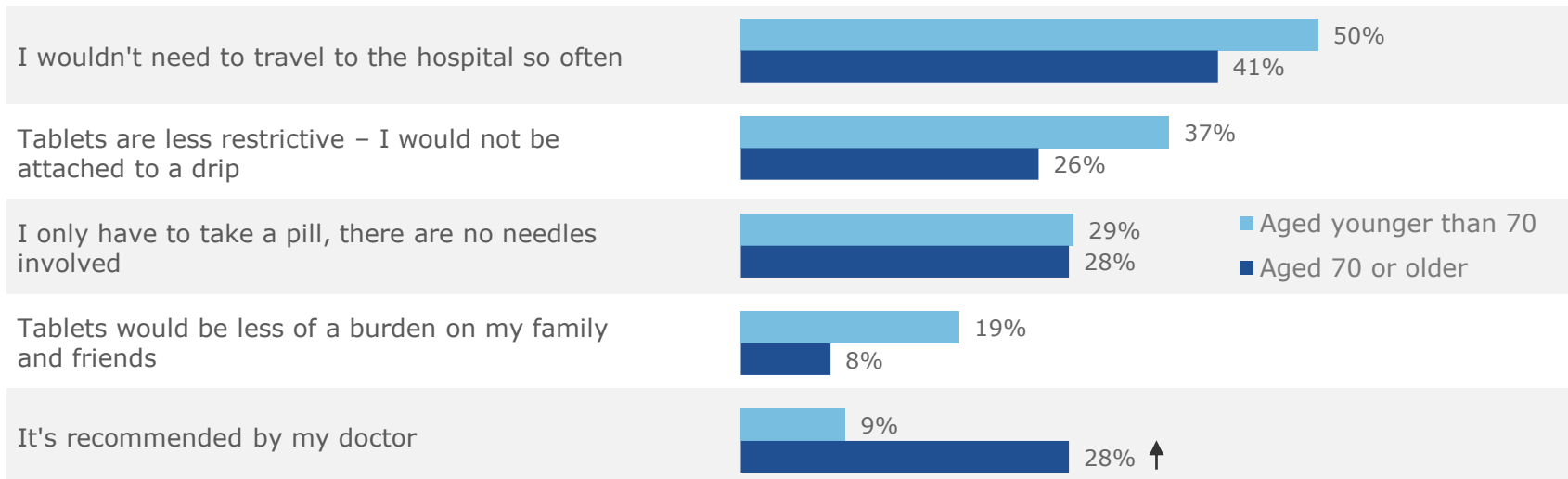
....Particularly amongst younger patients



Key reasons for hypothetical preference by age group: **tablet only**

(% respondents who would prefer tablet-only treatment)

Respondents selected their Top 2 reasons



↑ Significantly higher than other group

Primary reasons for infusion/injection preference are a little more mixed



Key reasons for hypothetical preference: **infusion or injection only**

(% respondents who would prefer infusion or injection only treatment)

Respondents selected their Top 2 reasons



Base: Respondents who would prefer infusion or injection only treatment (n=27*) – Q8 – See note section for details

* CAUTION: LOW BASE

See Appendix for more information

The perception of a stronger treatment taken for a fixed period of time drives a preference for combination treatment

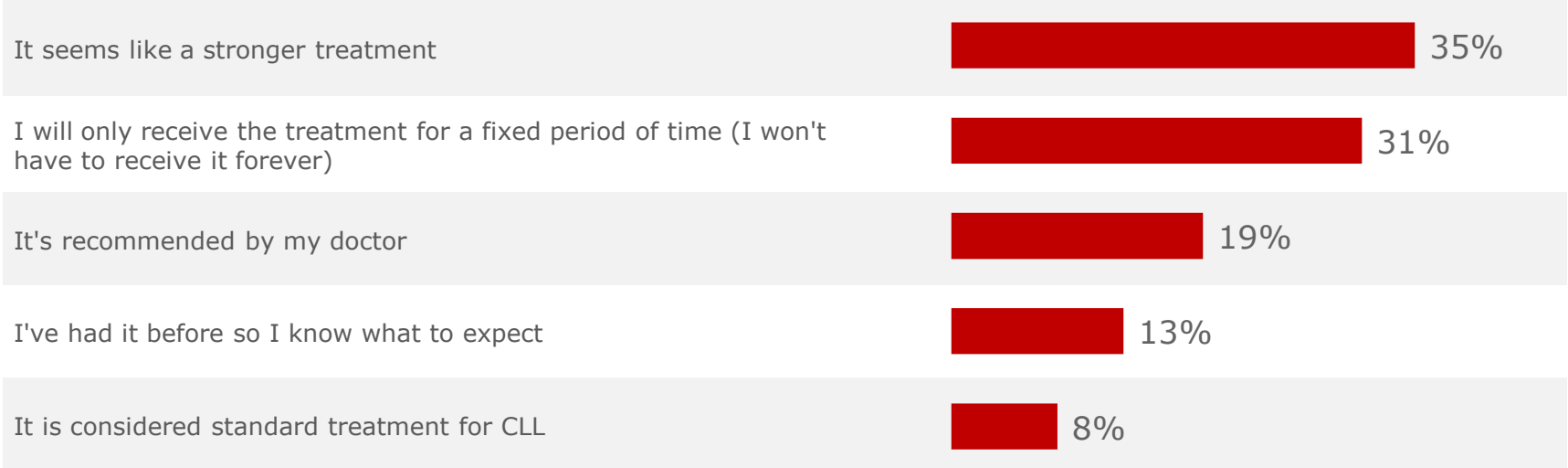


19%

Key reasons for hypothetical preference: **combination**

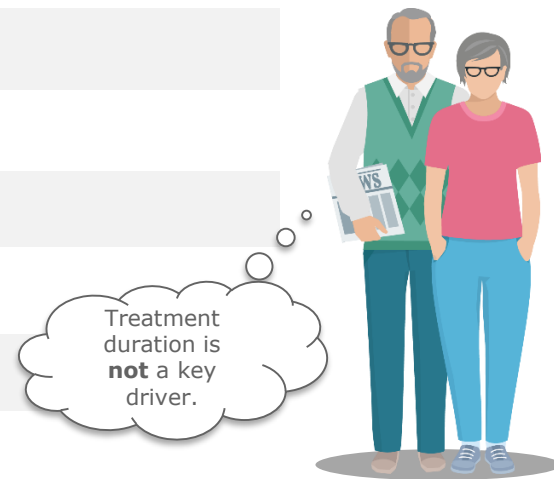
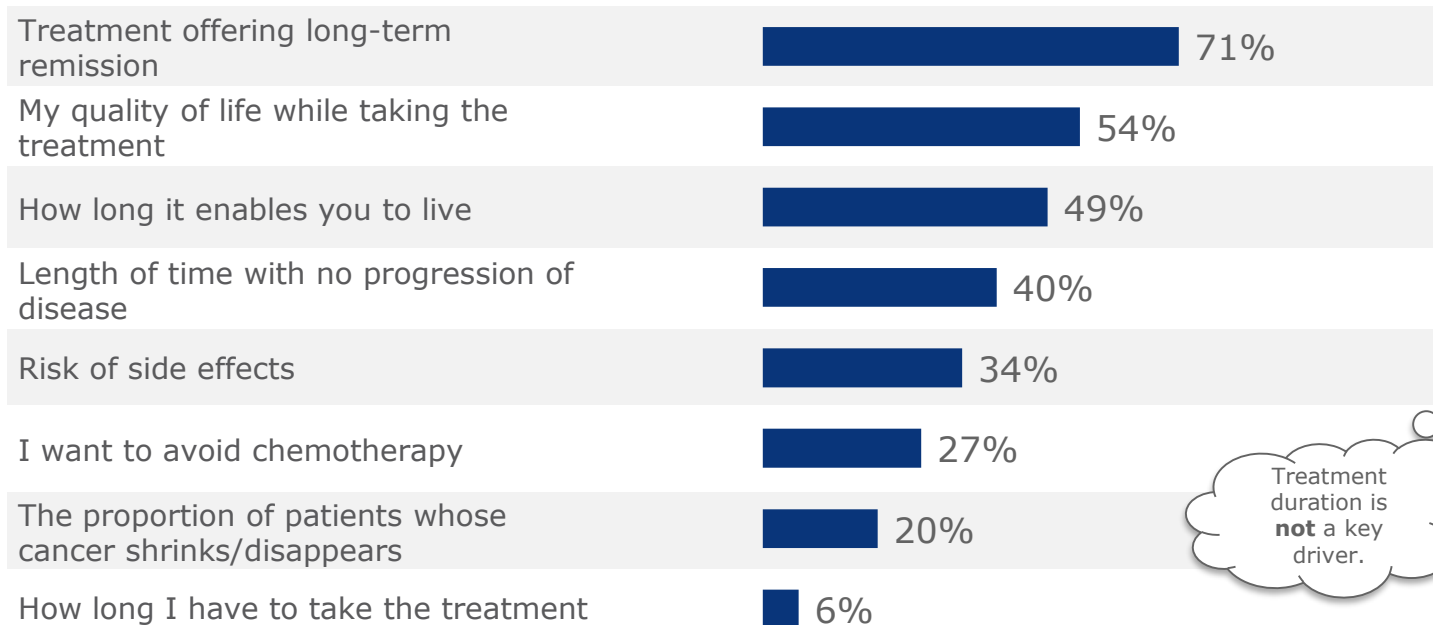
(% respondents who would prefer combination treatment)

Respondents selected their Top 2 reasons



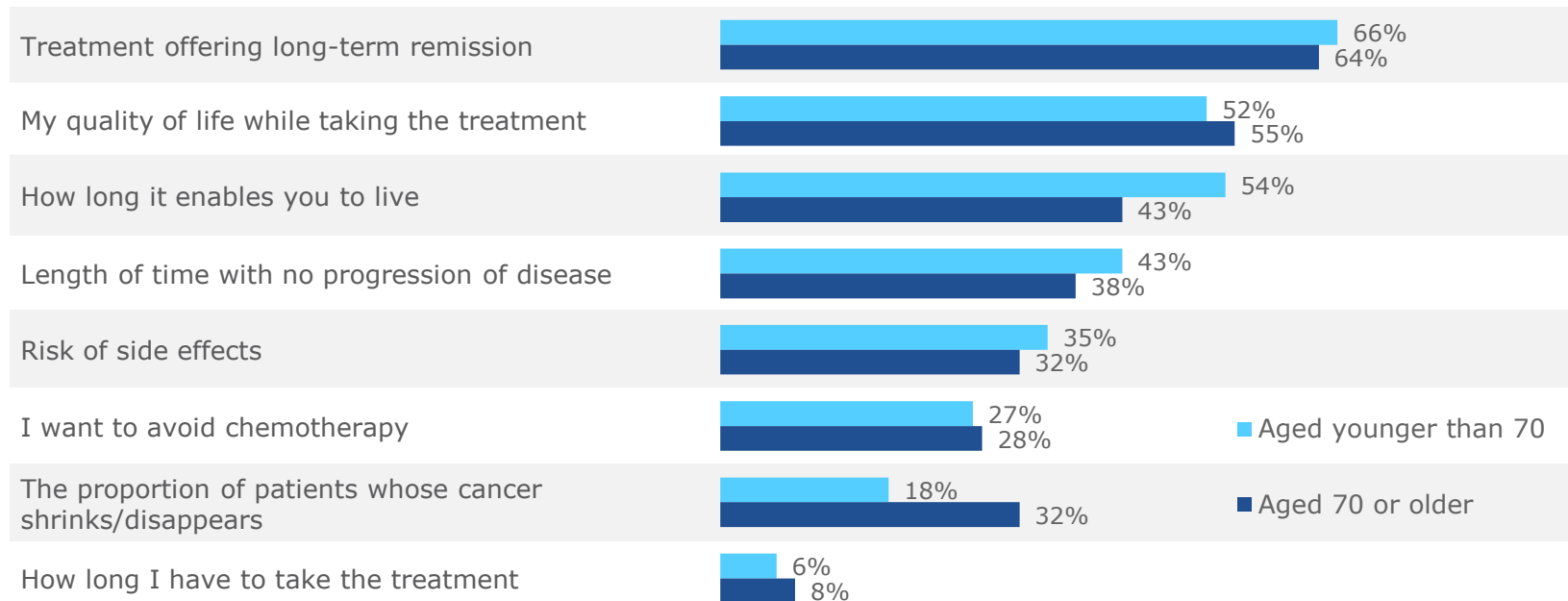
Overall, efficacy and quality of life are greater drivers of treatment choice than duration

Top 3 criteria in treatment decisions (% respondents treated or considering treatment)

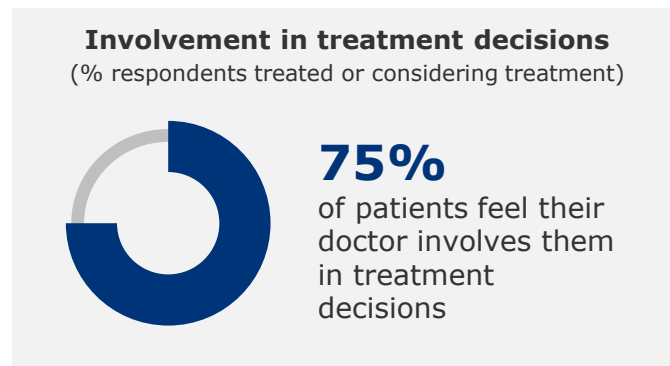
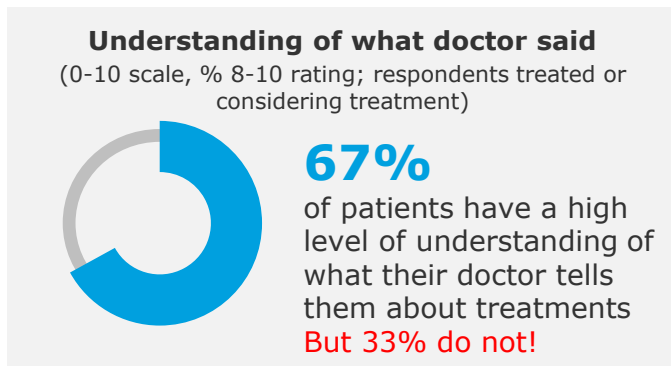
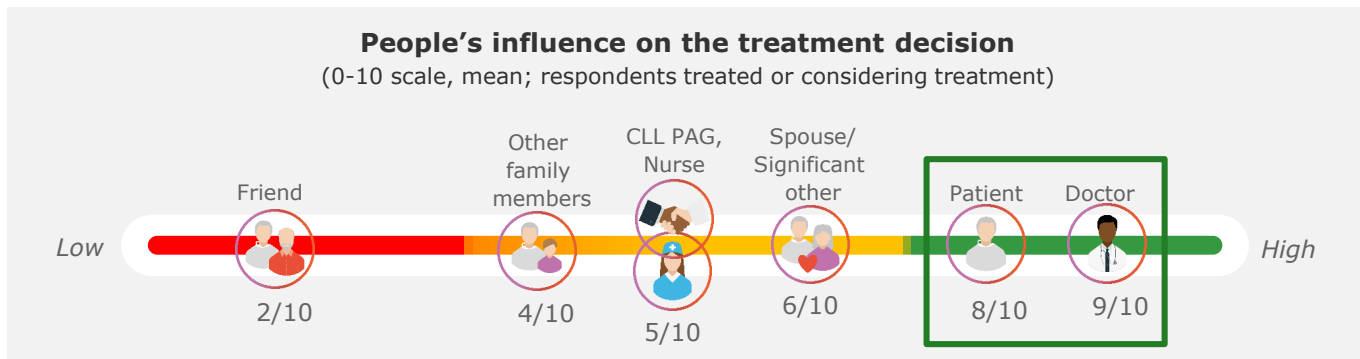


Younger patients are more influenced than older patients by how long a treatment will enable them to live

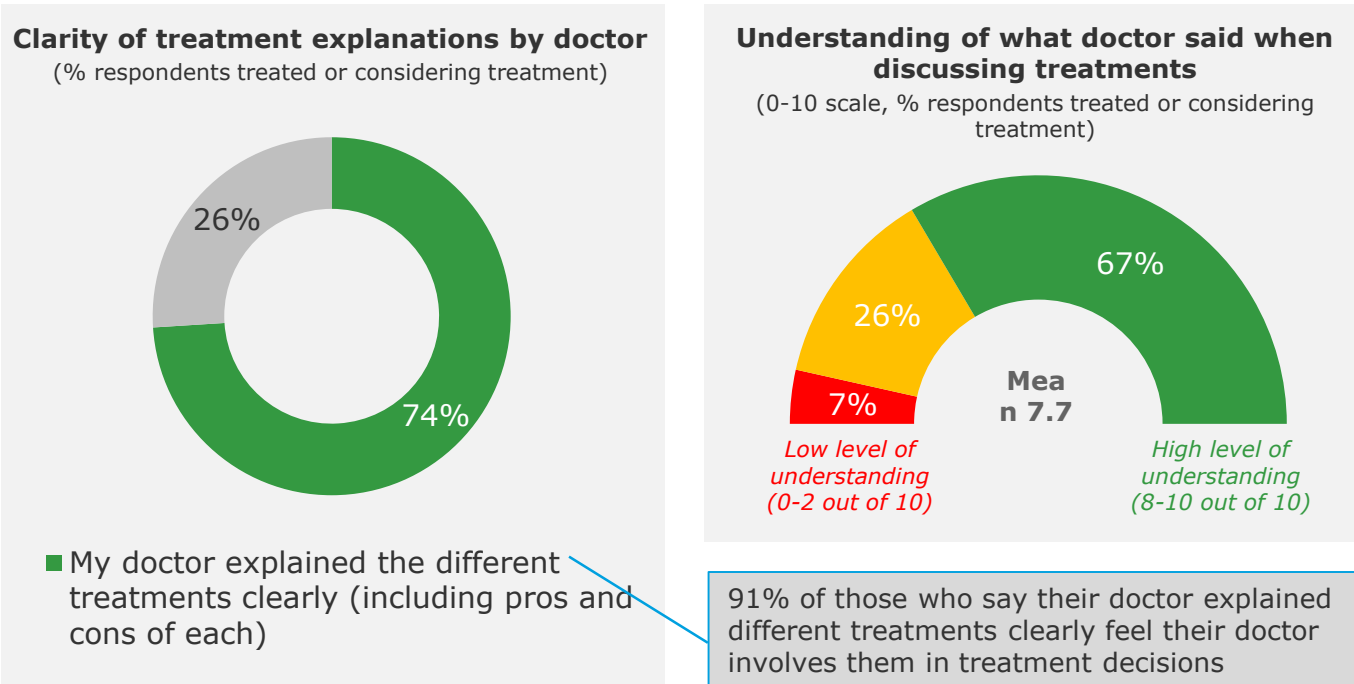
Top 3 criteria in treatment decisions
(% respondents treated or considering treatment)



Patients are active participants in treatment decisions



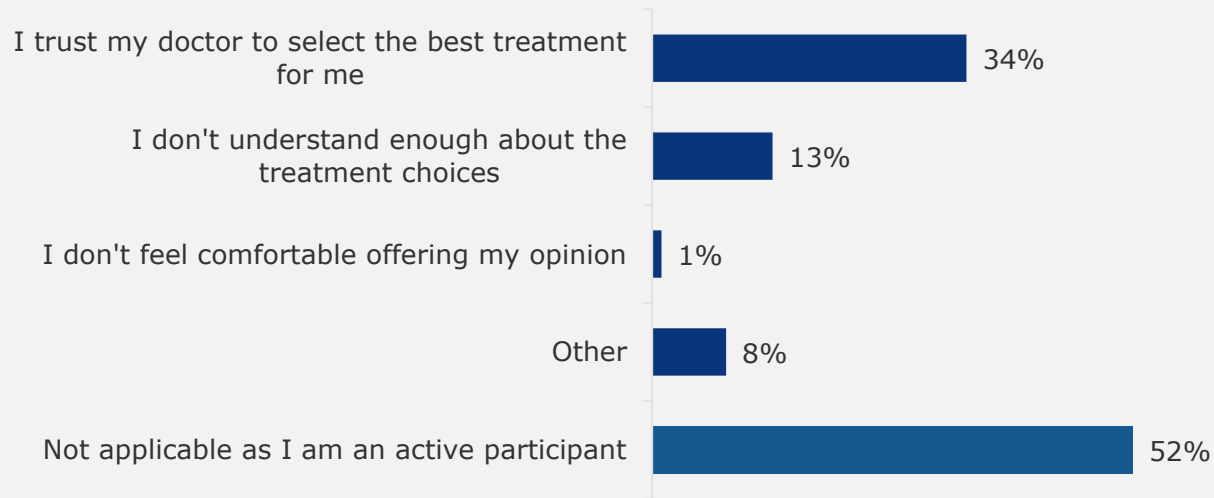
Patients feel they have a good understanding of treatment options based on discussions with their doctor



Base: Respondents who have received a treatment or are considering their first treatment (n=149) - Q13, Q14
See note section for details
See Appendix for more information

Those who are not an active participant generally trust their doctor to select the best treatment for them

Reasons for not feeling actively involved in medical decision-making for CLL treatment
(% respondents treated or considering treatment)



Market access is the main barrier preventing patients from trying a particular treatment



26% of patients treated or considering treatment have **wanted to try** a particular treatment **but were not able to**

No significant difference between those on tablet treatment and those not



Reasons why patients were unable to try a treatment

(% respondents who were unable to try a treatment)

Not available in my healthcare system/ country/ at my hospital 68%

I was told it was too expensive 24%

My doctor wanted to use it at a later stage 16%

My doctor would not support the decision 8%

Other 16%

Base: Respondents who have received a treatment or are considering their first treatment (n=149) - Q19

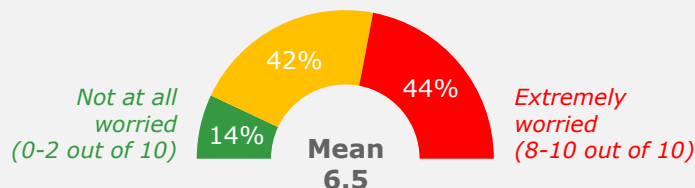
Base: Respondents who were unable to try a treatment (n=38) - Q20

See note section for details

Many patients are worried about their CLL symptoms returning

Worries about symptoms returning

(0-10 scale; % all respondents)



➔ **CLL patients in EU4 and CEE are significantly more worried about symptoms returning**

	Not at all worried	Extremly worried	Mean
EU4	7%	54%	↑ 7.1 ↑
CEE	14%	62%	↑ 7.4 ↑
Nordics	20%	30%	5.8
Rest of Europe	22%	41%	6.2
Rest of World	13%	35%	6.1

➔ **CLL patients who have received treatment are significantly more worried about symptoms returning**

	Not at all worried	Extremly worried	Mean
Treated	11%	50%	6.9 ↑
Not treated	17%	37%	6.0

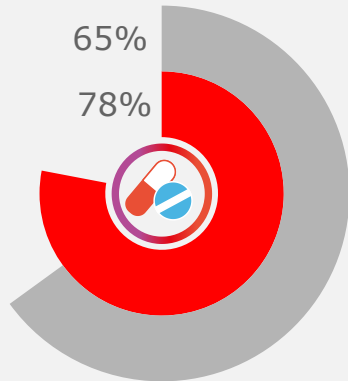
Higher level of worry in EU4 might be driven by higher proportion of treated patients (67% vs 53% in non-EU4)

↑ Significantly higher than other groups in the table

Those who are extremely worried tend to be more adherent on tablet and feel less involved in treatment decisions

Adherence level on tablet treatment

(% respondents treated with tablet who have never missed a dose)



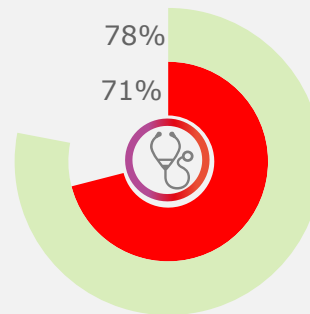
Lower level of worry (0-7 out of 10)

High level of worry (8-10 out of 10)



Involvement in treatment decisions

(% respondents treated or considering treatment who feel their doctor involves them in decisions)

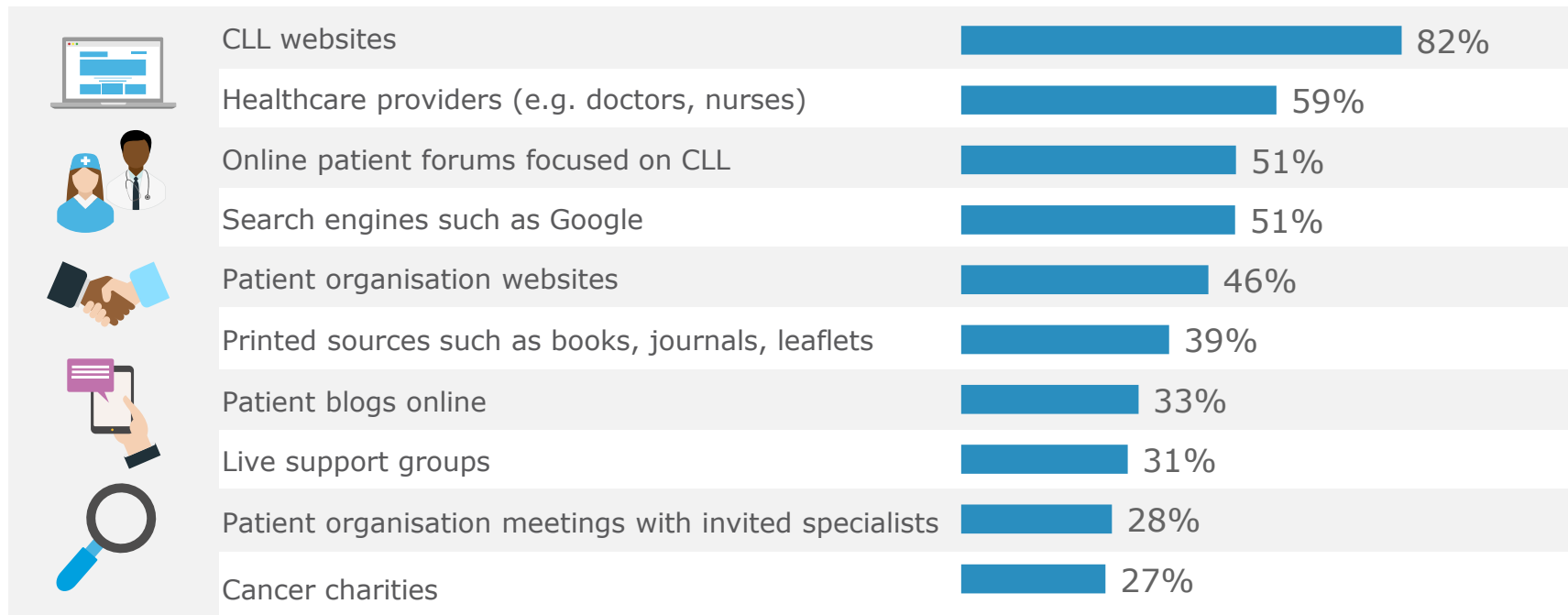


Of those treated/considering treatment, the **level of understanding** of their doctor's explanations is lower for extremely worried patients than for less worried ones (mean **6.9 vs 8.3**).

Clear information about treatment options should be provided on CLL websites

Top 10 sources of information for CLL

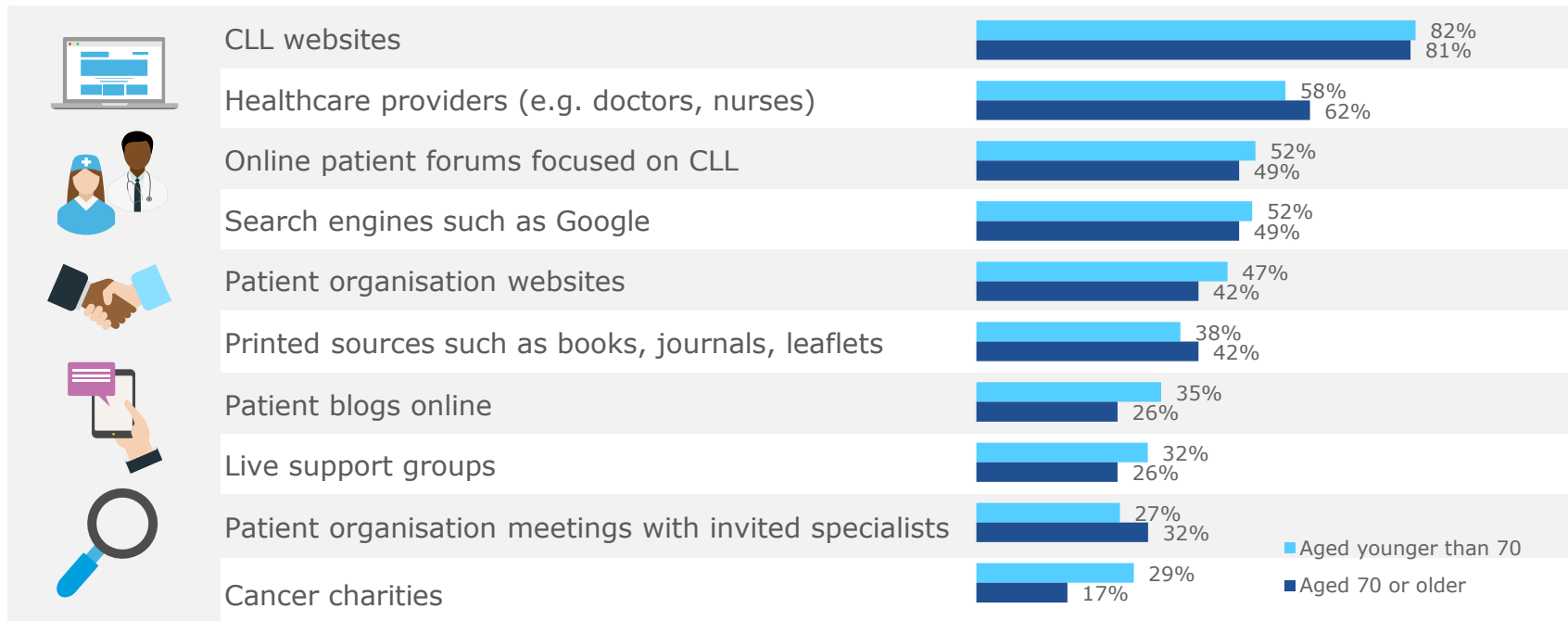
(% all respondents)



Both younger and older patients rely on CLL websites for information

Top 10 sources of information for CLL

(% all respondents)



Summary



MAJORITY OF PATIENTS PREFER TABLET

The majority of patients would prefer tablet treatment over infusion, injection or combinations, primarily **driven by the lower impact on daily life.**

Duration of treatment is less of a factor in treatment decisions than the **desire for long-term remission, overall survival, and good quality of life.**



PATIENTS ARE INVOLVED IN TREATMENT DECISIONS

Patients are **actively involved** in treatment decisions and **feel they understand** what their doctor explains.

However, a third do not fully understand their doctor, so there is room for Janssen to provide clear and accessible information about treatment options to CLL patients.



PATIENTS SEARCH FOR INFORMATION

CLL websites, healthcare providers, and online search engines are key sources of information to patients.

Therefore, the best way for Janssen to make information about treatment options available to patients would be via CLL websites or leaflets at doctors' practices.



PATIENTS ON TABLET ARE HIGHLY COMPLIANT

The majority of patients on tablet treatment have **never missed a dose**, which should counter the pushback from doctors who raise adherence concerns.

The more worried patients are about their symptoms returning, the more adherent they tend to be.

80% of patients **use techniques for adherence.** Reminder apps are rarely used.

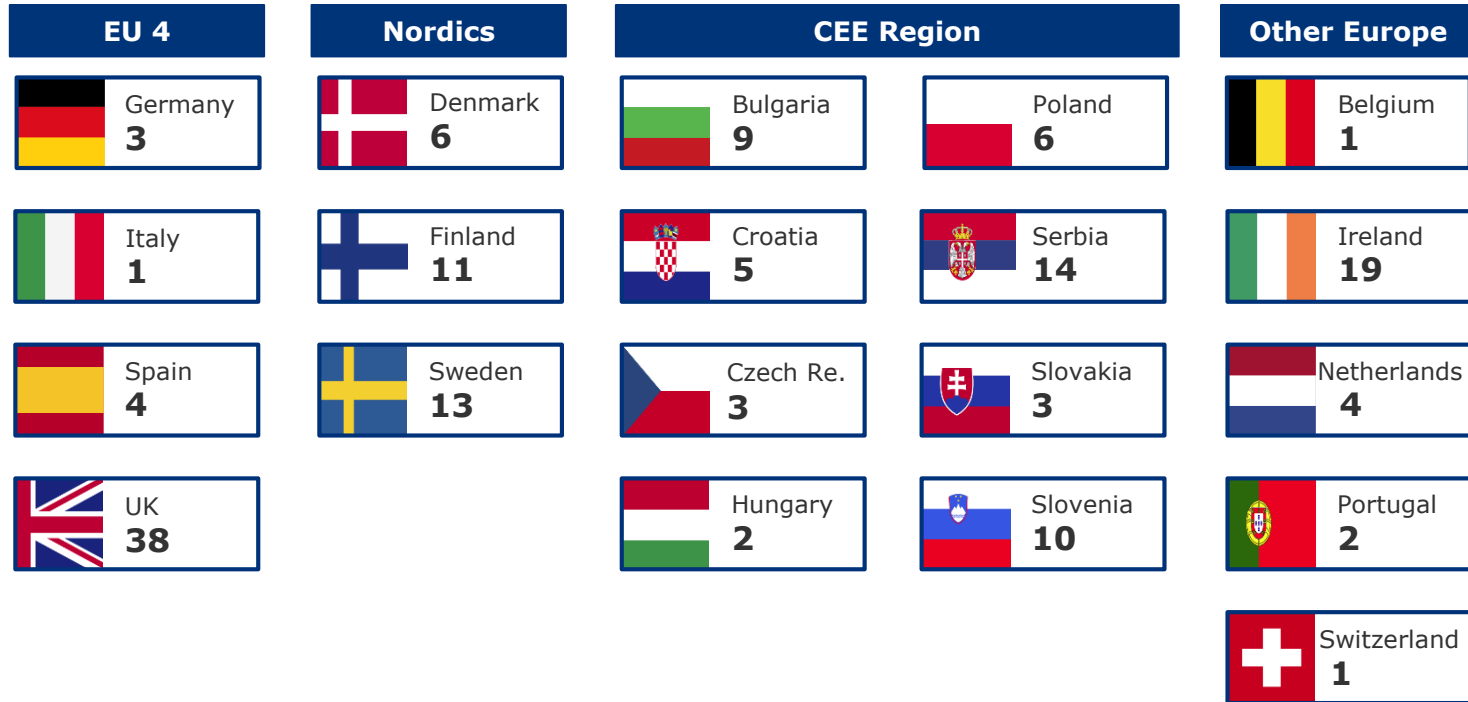


TREATMENT SATISFACTION IS HIGH

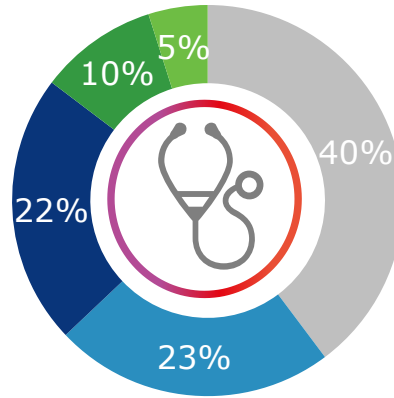
Patients on tablet-only treatment are more satisfied than those on infusion or combination treatment, rating them 9 out of 10.

Appendix

A total of 155 CLL patients from across Europe participated

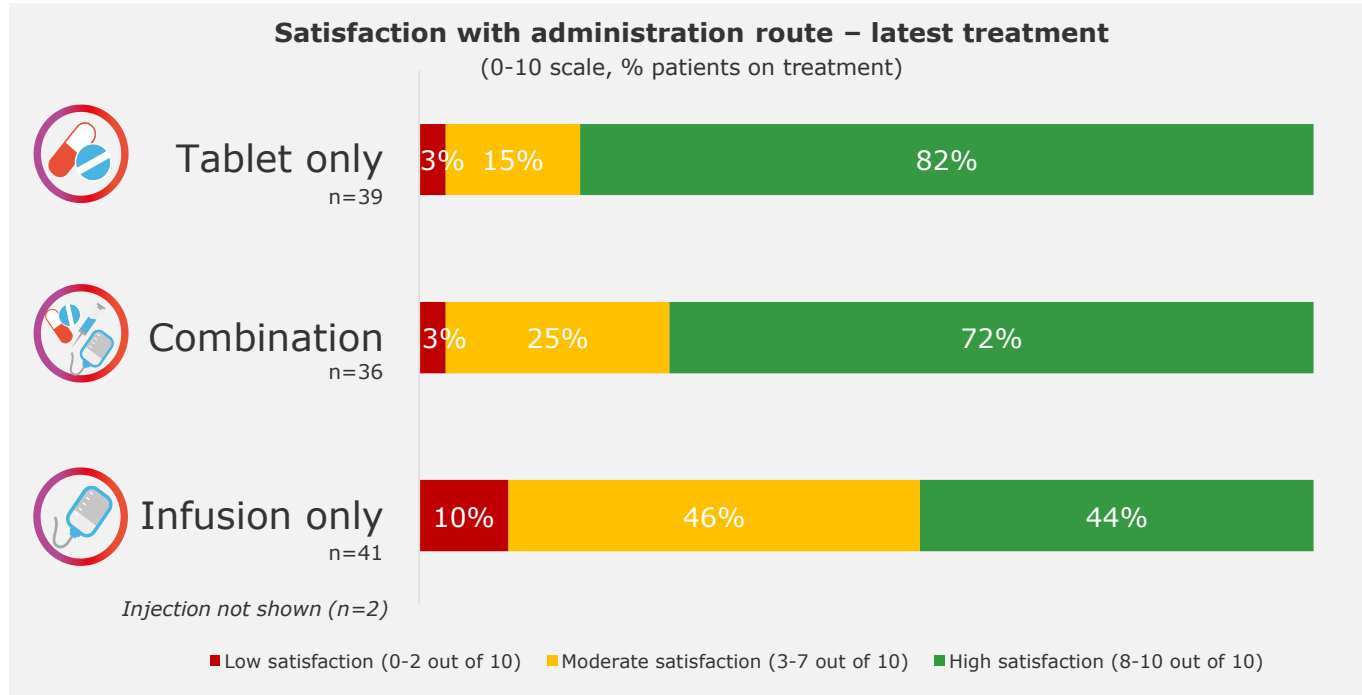


The majority of respondents have discussed treatment options with their doctor before



- I have not been treated yet
- I am in remission / in between treatments and currently NOT receiving treatment
- I am considering or receiving my second or later treatment

There is very little dissatisfaction with CLL treatment administration routes



Base: Respondents who have received each treatment (Tablet n=39; Combination n=36; Infusion n=41) - Q4a
See note section for details

Amongst those who would prefer tablet treatment, those who have received combination treatment place most value on not having to travel to the hospital

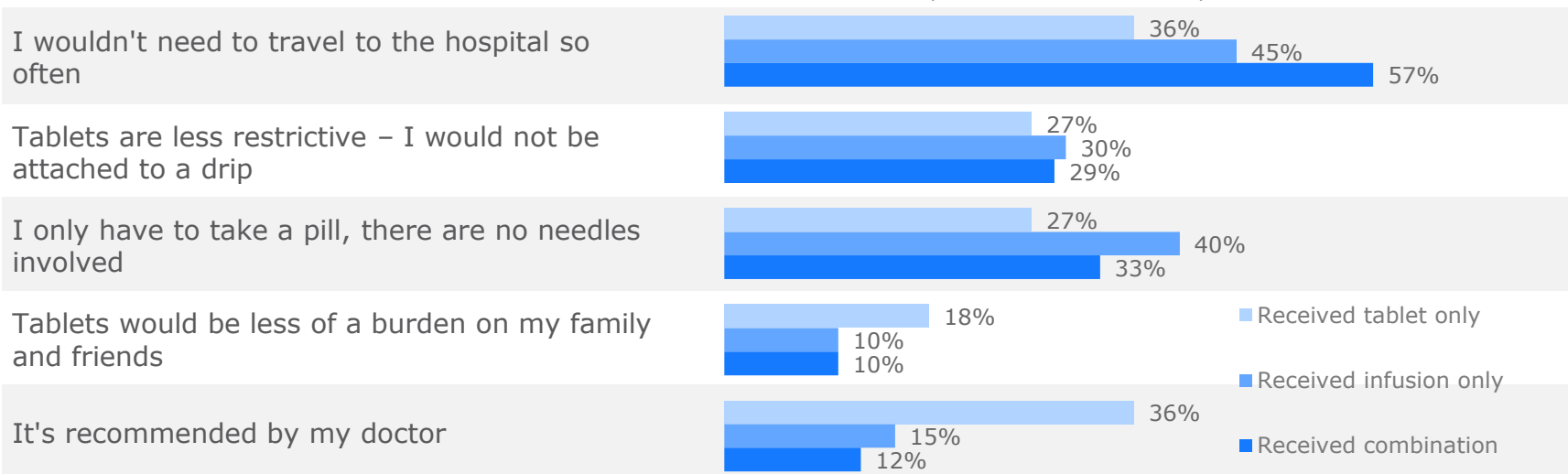
 **70%**

Key reasons for hypothetical preference

by treatment experience: **tablet only**

(% respondents who would prefer tablet-only treatment)

Respondents selected their Top 2 reasons



Injection not shown (n=2)

Base: Respondents who would prefer tablet only treatment by treatment experience (All n=172; Respondents who have only ever received tablet n=11*; Respondents who have only ever received infusion treatment n=20*; Respondents who have received a combination n=49) - Q6

- See note section for details

* CAUTION: LOW BASE

Key reasons for hypothetical preference: tablet only

(% respondents who would prefer tablet only treatment)

	<i>% to select item as a Top 2 reason</i>	<i>% to select item as a reason</i>
I wouldn't need to travel to the hospital so often	48%	78%
Tablets are less restrictive – I would not be attached to a drip	34%	70%
I only have to take a pill, there are no needles involved	29%	61%
Tablets would be less of a burden on my family and friends	16%	54%
It's recommended by my doctor	13%	24%
I would have more flexibility around when to take the treatment	12%	39%
I think I would suffer fewer side effects	11%	27%
I would prefer to take a treatment every day rather than at longer intervals	6%	27%
It is considered standard treatment for CLL	6%	13%
It seems like a stronger treatment	5%	6%
I would prefer to take a treatment for a fixed period of time	4%	17%
I have had tablet treatment before so I know what to expect	3%	16%
I will continue to take the treatment, rather than stopping after a fixed period of time	2%	11%
Other	1%	2%

Key reasons for hypothetical preference: infusion or injection only

(% respondents who would prefer infusion or injection only treatment)

	<i>% to select item as a Top 2 reason</i>	<i>% to select item as a reason</i>
I would take my treatment at a fixed time	30%	30%
It means I would have regular contact with my doctor/nurse	26%	37%
I think I would suffer fewer side effects	22%	37%
It seems like a stronger treatment	22%	30%
I wouldn't have to remember to take my treatment everyday	19%	30%
I would only receive the treatment for a fixed period of time (I wouldn't have to receive it forever)	19%	30%
I have had injection / infusion treatment before so I know what to expect	7%	19%
An injection / infusion would be less of a burden on my friends and family	4%	15%
It is considered standard treatment for CLL	0%	4%
It's recommended by my doctor	0%	4%
It is administered via a needle	0%	0%
Other	7%	11%

Base: All respondents who would prefer infusion or injection only treatment (n=27*) – Q7, Q8 – See note section for details

* CAUTION: LOW BASE

Key reasons for hypothetical preference: combination

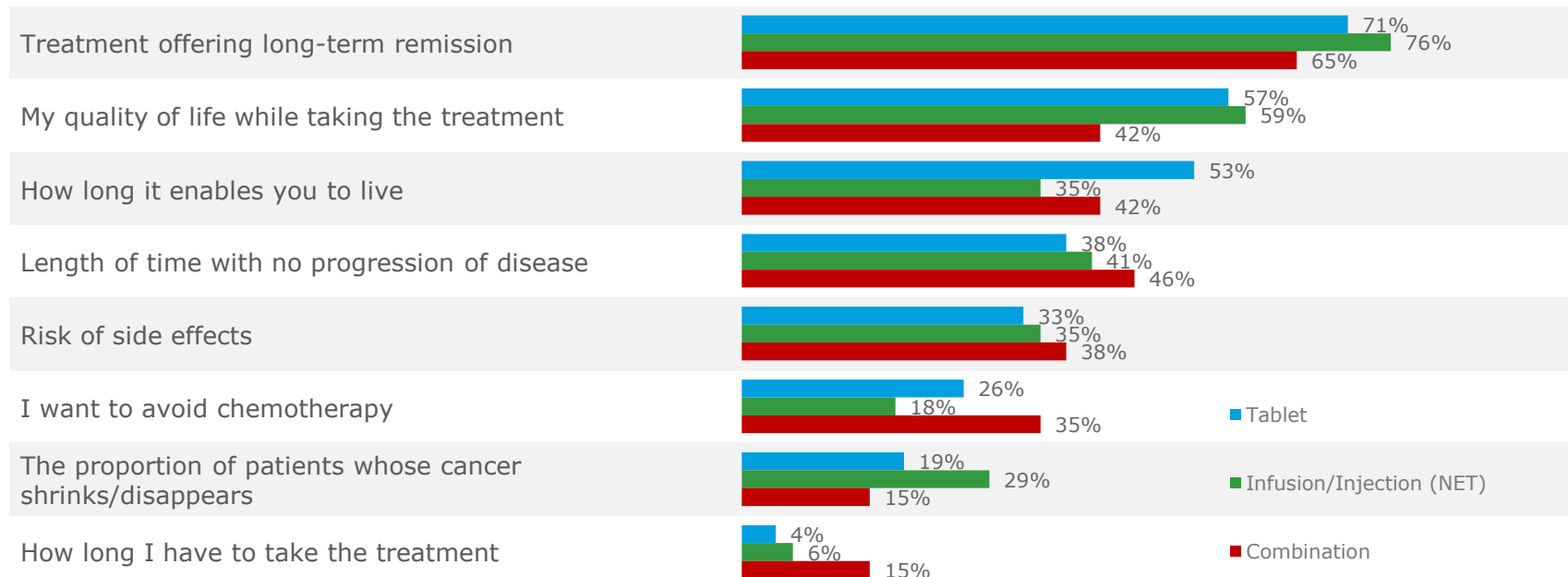
(% respondents who would prefer combination treatment)

	<i>% to select item as a Top 2 reason</i>	<i>% to select item as a reason</i>
It seems like a stronger treatment	35%	38%
I will only receive the treatment for a fixed period of time (I won't have to receive it forever)	31%	35%
It's recommended by my doctor	19%	19%
I've had it before so I know what to expect	13%	17%
It is considered standard treatment for CLL	8%	8%
Other	17%	17%

Those who prefer tablet place least importance on treatment duration in decision making

Top 3 criteria in treatment decisions by treatment preference

(% respondents treated or considering treatment)



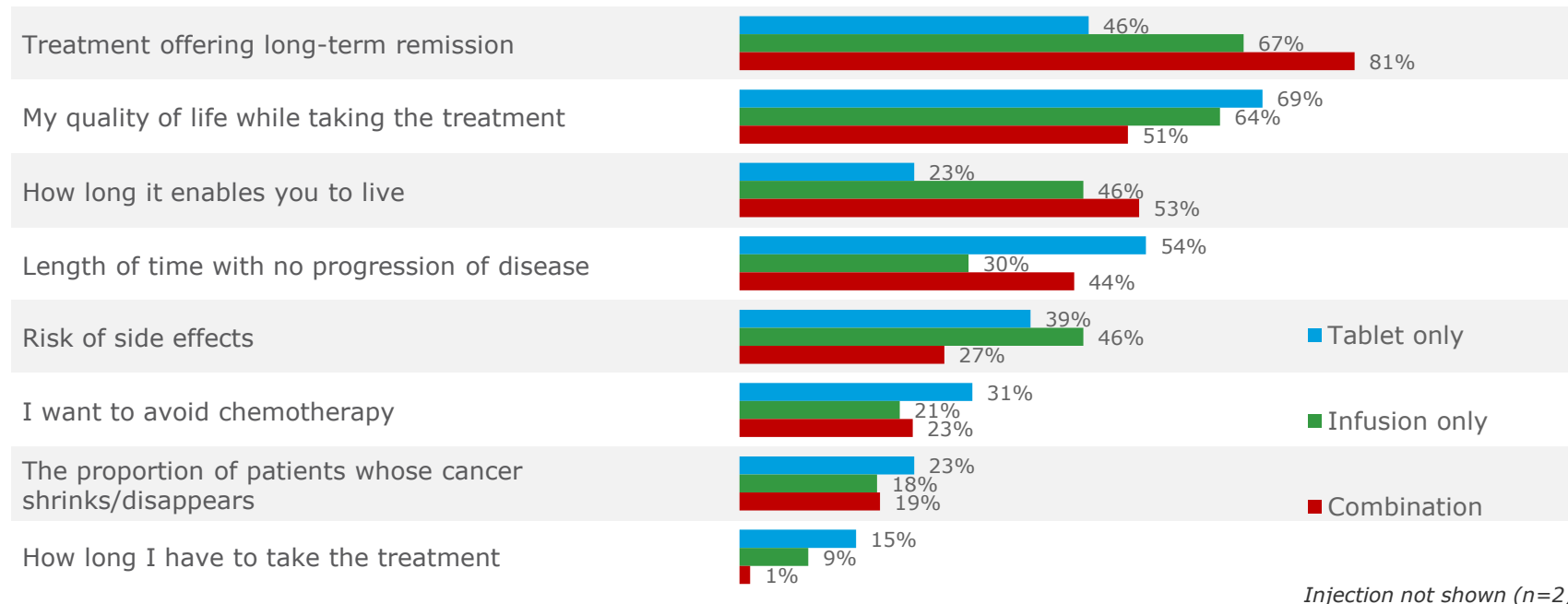
Base: Respondents who prefer each administration route (All n=149; Respondents who prefer tablet only n=106; Respondents who prefer injection/infusion n=17*; Respondents who prefer a combination n=26*) - Q11 - See note section for details

* CAUTION: LOW BASE

Those treated with tablet tend to be driven by quality of life more than long-term remission

Top 3 criteria in treatment decisions by treatment experience

(% treated respondents)



Base: Respondents who experienced each administration route (All n=118; Respondents who have only ever received tablet n=13*; Respondents who have only ever received infusion n=33; Respondents who have had a combination n=70) - Q11 - See note section for details

* CAUTION: LOW BASE

Tablet treatment is perhaps being given to patients who are more engaged in their treatment. Conversely, those with a higher level of understanding might be the ones who end up receiving tablet treatment



Understanding of treatment: those who have only ever received tablet treatment

n=13*; 77% <70 years



62% of patients have a high level of understanding of what their doctor tells them about treatments



77% of patients said the doctor explained the different treatment options clearly (including pros and cons of each)

Low



High

8/10 Patients rate their own influence in treatment decisions as 8/10 (high)



Understanding of treatment: those who have only ever received infusion treatment

n=33; 76% <70 years



49% of patients have a high level of understanding of what their doctor tells them about treatments



58% of patients said the doctor explained the different treatment options clearly (including pros and cons of each)

Low



High

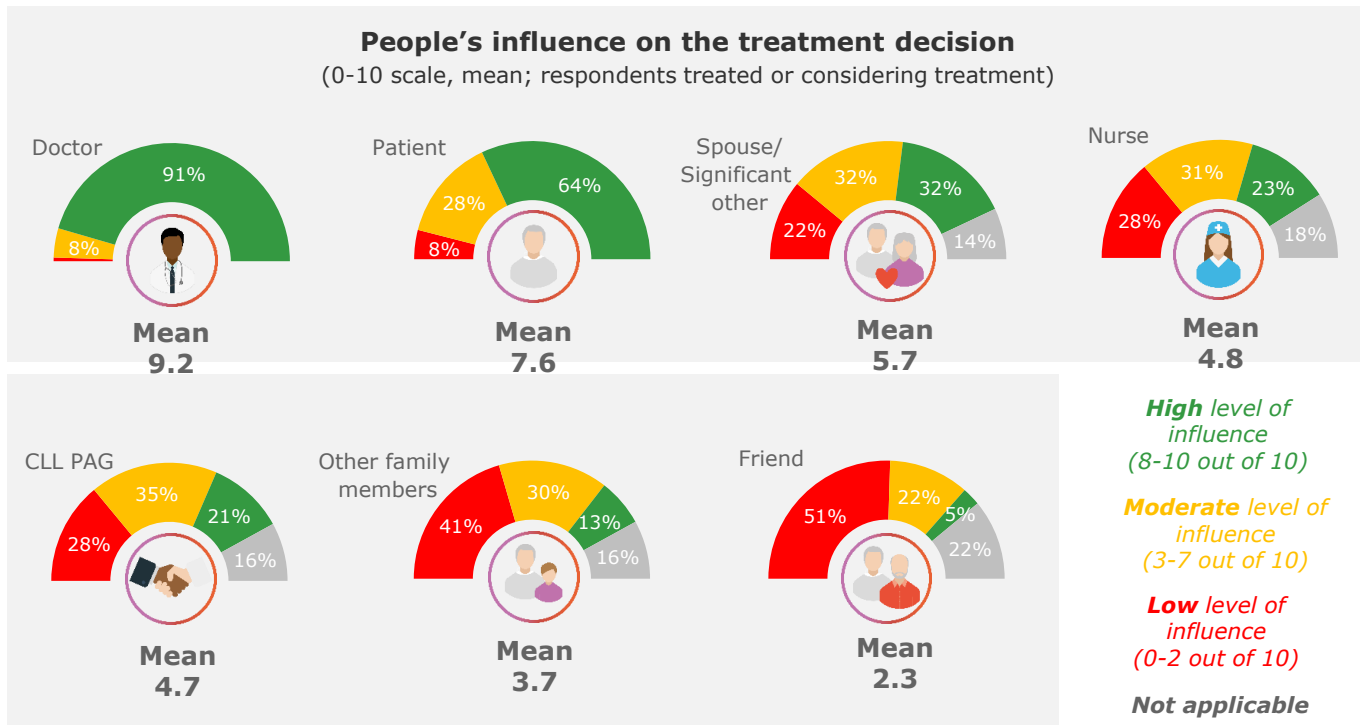
7/10 Patients rate their own influence in treatment decisions as 7/10 (high)

■ Low understanding (0-2 out of 10) ■ Moderate understanding (3-7 out of 10) ■ High understanding (8-10 out of 10) *Injection not shown (n=2)*

Base: Respondents who have received a treatment (Tablet n=13*; Infusion n=33) - Q12, Q13, Q14 - See note section for details

* CAUTION: LOW BASE








The doctor is the primary influence in treatment decisions for the vast majority



Doctor and patient are most important in treatment decisions regardless of age or gender

People's influence on the treatment decision

(0-10 scale, mean; respondents treated or considering treatment per age group/gender)








	Younger than 70 (n=112)	70 or older (n=37)		Male (n=72)	Female (n=76)	
 Doctor	9	10		9	9	High level of influence (8-10 out of 10)
 Patient	7	8		7	8	
 Spouse/ Significant other	6	6		6	5	Moderate level of influence (3-7 out of 10)
 CLL Patient Advocacy Group	5	5		5	5	
 Nurse	5	5		5	4	
 Other family members	4	3		4	4	Low level of influence (0-2 out of 10)
 Friend	2	2		2	3	

Base: Respondents who have received a treatment or are considering their first treatment per region (n=149) - Q12
See note section for details

Doctor and patient are most important in treatment decisions across regions

People's influence on the treatment decision

(0-10 scale, mean; respondents treated or considering treatment per region)

	EU4 (n=32)	CEE (n=32)	Nordics (n=16*)	Rest of Europe (n=19*)	Rest of world (n=50)	
 Doctor	9	9	10	9	9	High level of influence (8-10 out of 10)
 Patient	7	7	6	9	9	
 Spouse/ Significant other	5	6	5	6	6	Moderate level of influence (3-7 out of 10)
 CLL Patient Advocacy Group	4	5	1	5	6	
 Nurse	6	5	4	5	4	
 Other family members	3	5	4	5	3	Low level of influence (0-2 out of 10)
 Friend	2	3	1	3	2	

Base: Respondents who have received a treatment or are considering their first treatment per region (n=149) - Q12

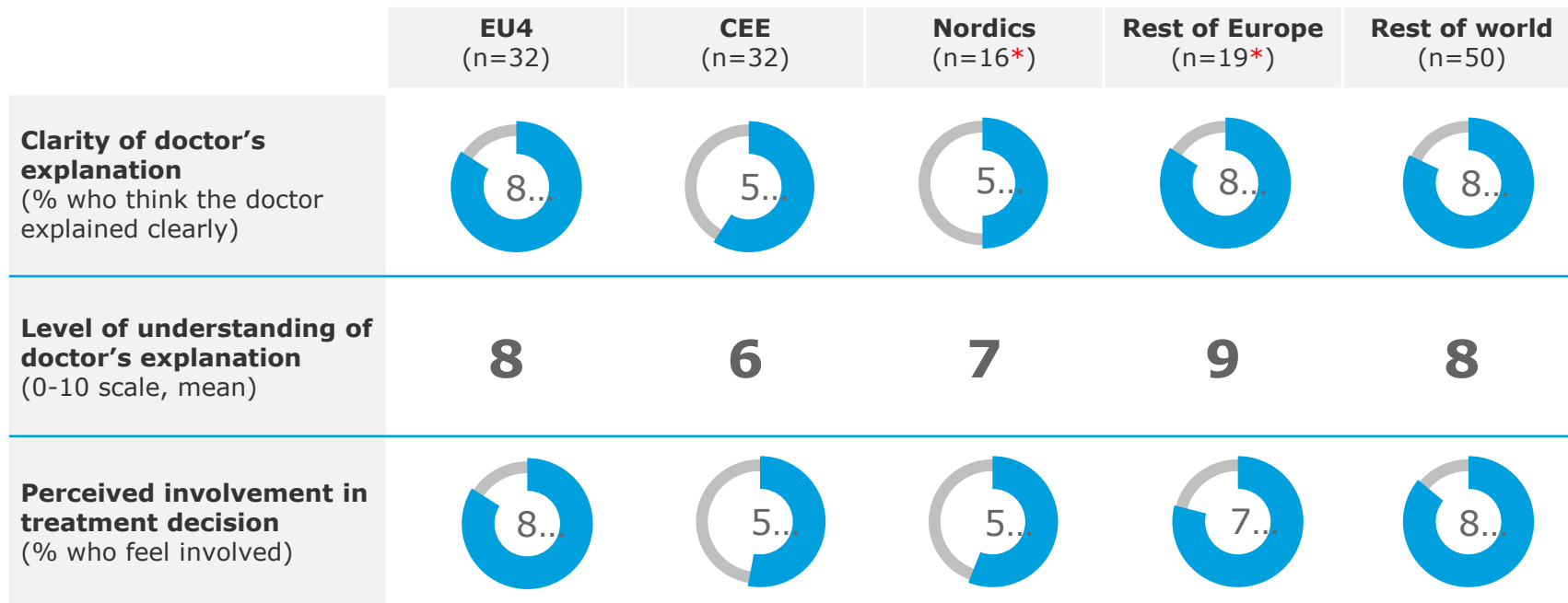
See note section for details

* CAUTION: LOW BASE

Patients in CEE and Nordics understand their doctor's explanation least and feel least involved

Patients' understanding and influence on the treatment decision

(Respondents treated or considering treatment per region)



Base: Respondents who have received a treatment or are considering their first treatment per region (n=149) - Q13, Q14, Q16









- See note section for details

* CAUTION: LOW BASE

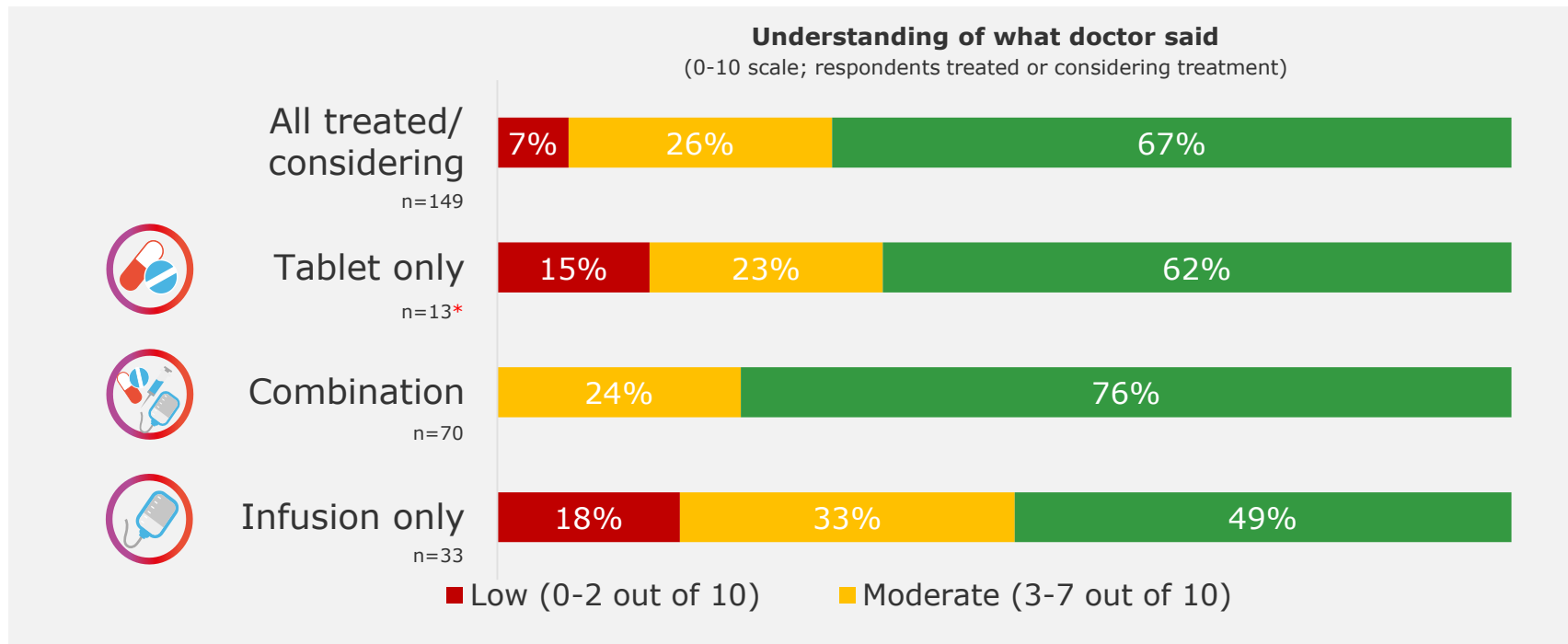
Involvement in treatment decisions is high for both younger and older patients

Patients' understanding and influence on the treatment decision

(Respondents treated or considering treatment by age and by gender)

	Age		Gender	
	Younger than 70 (n=112)	70 or older (n=37)	Male (n=72)	Female (n=76)
Clarity of doctor's explanation (% who think the doctor explained clearly)				
Level of understanding of doctor's explanation (0-10 scale, mean)	8	8	8	8
Perceived involvement in treatment decision (% who feel involved)				

Patients who have received any treatment combination understand their doctors best

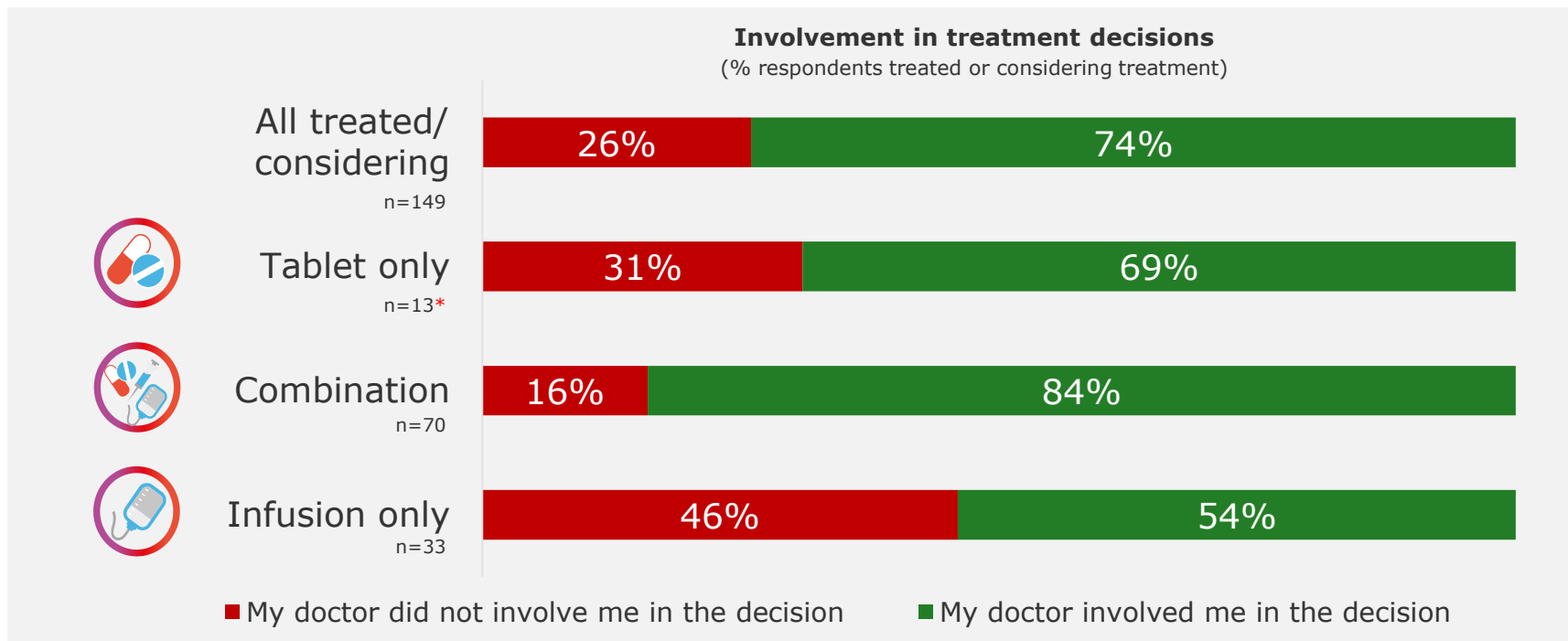


Base: Respondents who have received a treatment or are considering their first treatment (n=149) - Q14

See note section for details

* CAUTION: LOW BASE

Patients who have received any combination feel most involved in treatment decisions



Base: Respondents who have received a treatment or are considering their first treatment (n=149) - Q16
See note section for details

* CAUTION: LOW BASE

CLL websites are the primary source of information across all regions, but those in CEE are more likely to use printed resources than patients in other regions

Top 10 sources of information for CLL
(% all respondents)

	EU4 (n=46)	CEE (n=52)	Nordics (n=30)	Rest of Europe (n=27*)	Rest of world (n=92)	
CLL websites	89%	67%	70%	89%	88%	High usage (70-100%)
Healthcare providers (e.g. doctors, nurses)	57%	58%	73%	52%	58%	
Online patient forums focused on CLL	54%	37%	50%	33%	64%	Moderate usage (30-69%)
Search engines such as Google	44%	58%	63%	52%	47%	
Patient organisation websites	46%	40%	47%	33%	52%	
Printed sources such as books, journals, leaflets	35%	52%	30%	37%	37%	
Patient blogs online	24%	25%	33%	26%	44%	Low usage (0-29%)
Live support groups	24%	25%	23%	26%	41%	
Patient organisation meetings with invited specialists	20%	35%	27%	33%	27%	
Cancer charities	48%	14%	23%	33%	23%	

Base: All respondents (n=247) - Q21 - See note section for details

* CAUTION: LOW BASE

The majority of respondents found the survey through online sources

How respondents heard about the Patient Voices Survey
(% all respondents)

