CLL Patient Voices Survey
Final Report

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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
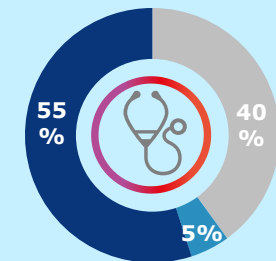
Europe n=155

US n=67

Rest of world n=25

Gender:

53%   47%
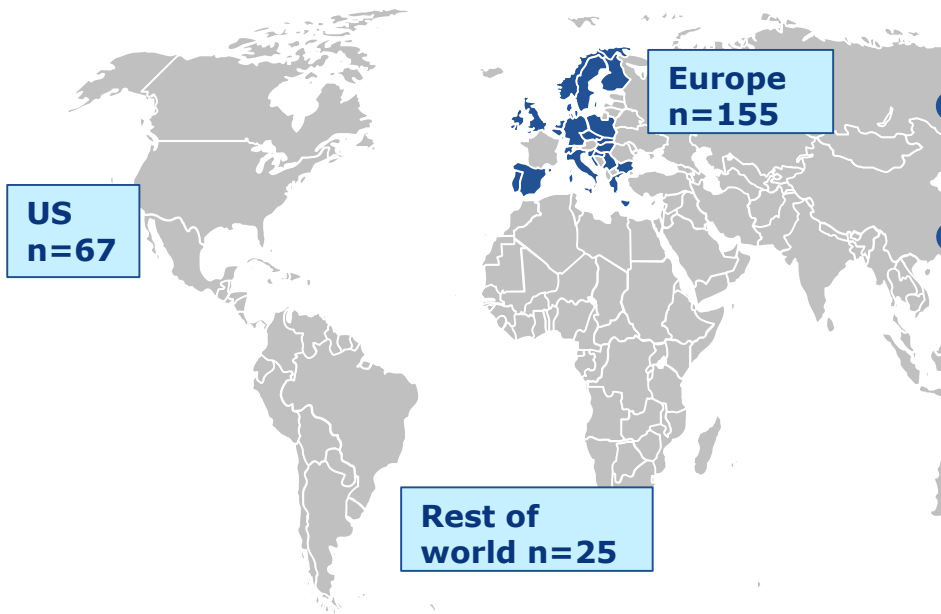
Age:
63 years (median)
21% ≥70 years

Treatment status:

55%   40%

5%

■ 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
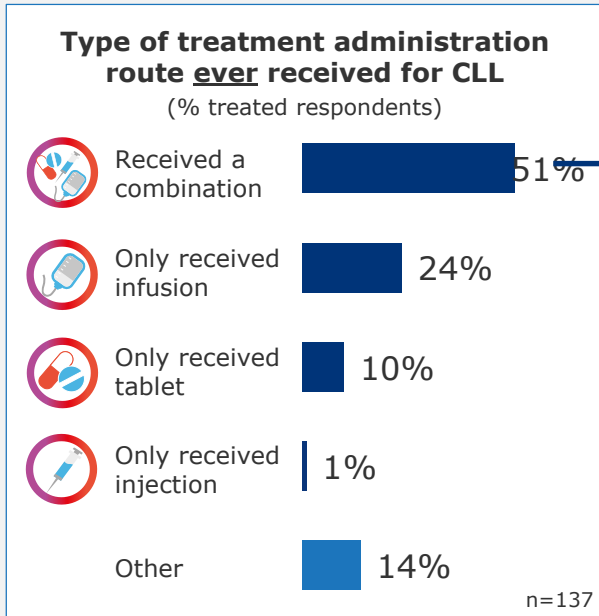
45% of CLL patients have not received treatment

Type of treatment administration route <u>ever</u> received for CLL
(% treated respondents)

Received a combination — 51%

Only received infusion — 24%

Only received tablet — 10%

Only received injection — 1%

Other — 14%

n=137

Latest administration route received
(% respondents treated with combinations)

43%

37%

12%

6%

1%

1%

0%

87%

n=70

Q1, Q3a, Q3b - See note section for details
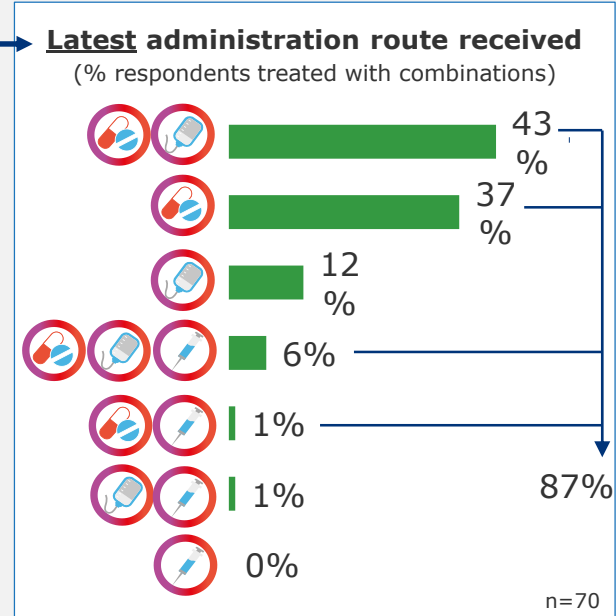
Patients on tablet-only are more satisfied than those using other administration routes

Satisfaction with administration route – latest treatment
(0-10 scale, mean; treated respondents)

Low | High

Injection not shown (n=2)

7/10   8/10   9/10

Those patients who have only ever received infusion treatment *or* their latest treatment has been infusion only (30% of treated patients)

Those patients whose latest treatment is combination treatment (26% of treated patients)

Those patients who have only ever received tablet treatment *or* their latest treatment has been tablet only (28% of treated patients)

Those patients who have previously received combination treatment but their latest treatment is tablet-only are more satisfied with tablet treatment (9/10) than those patients who have only ever received tablet-only treatment (8/10)
n=26* and n=13* respectively

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
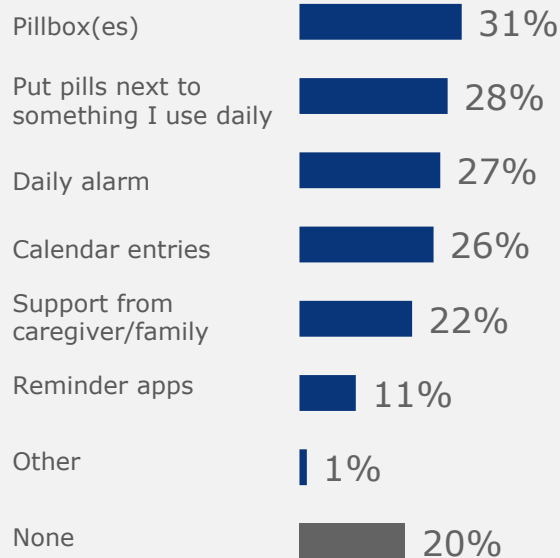See note section for details
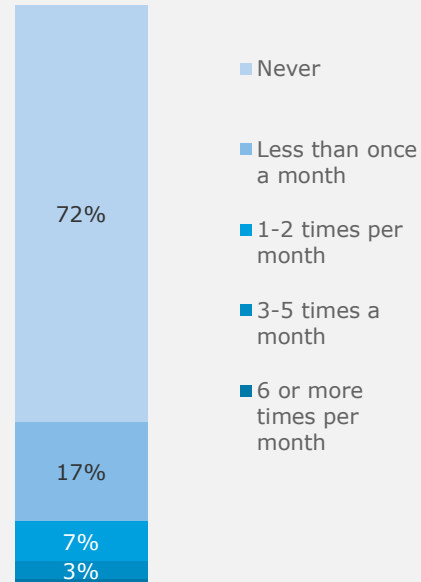* CAUTION: LOW BASE
See Appendix for more information

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)

Technique	%
Pillbox(es)	31%
Put pills next to something I use daily	28%
Daily alarm	27%
Calendar entries	26%
Support from caregiver/family	22%
Reminder apps	11%
Other	1%
None	20%

Frequency of missed doses
(% respondents treated with tablets)

- Never — 72%
- Less than once a month — 17%
- 1-2 times per month — 7%
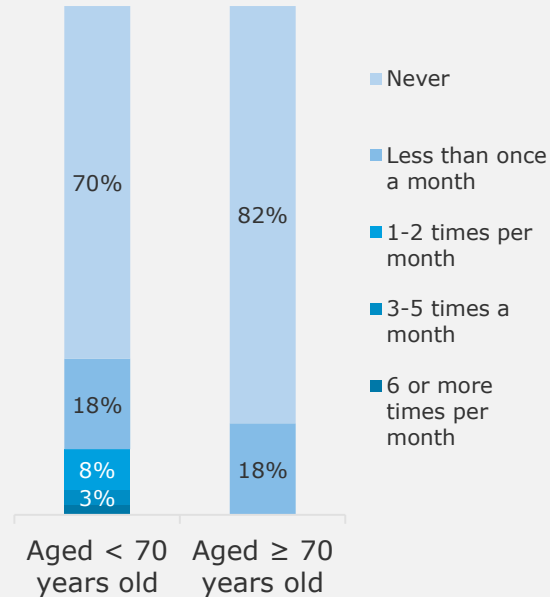- 3-5 times a month — 3%
- 6 or more times per month

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

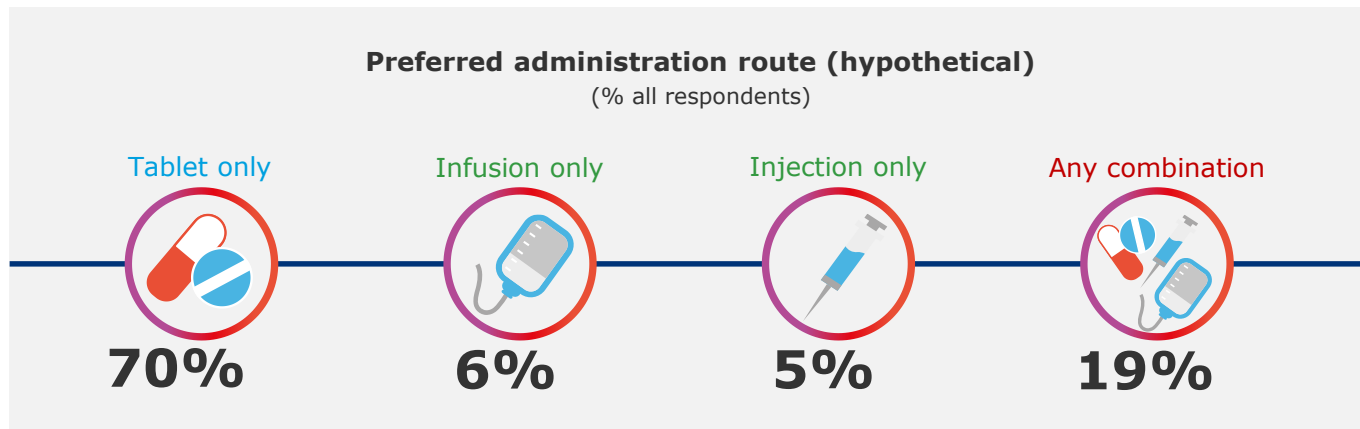## Techniques used for adherence
(% respondents treated with tablets)
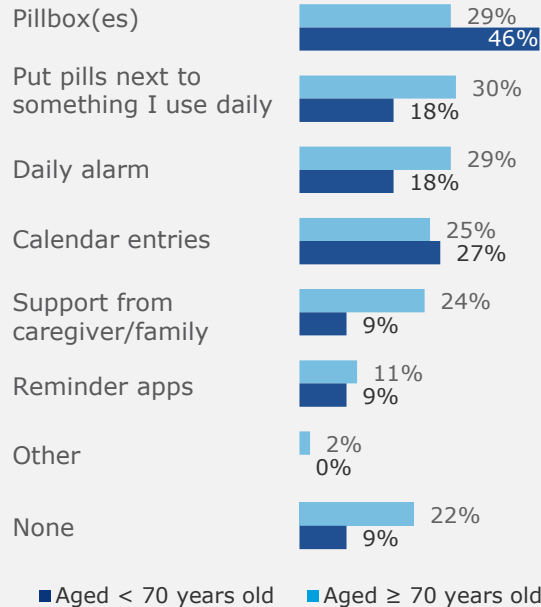
Technique	Aged ≥ 70 years old	Aged < 70 years old
Pillbox(es)	29%	46%
Put pills next to something I use daily	30%	18%
Daily alarm	29%	18%
Calendar entries	25%	27%
Support from caregiver/family	24%	9%
Reminder apps	11%	9%
Other	2%	0%
None	22%	9%

■ Aged < 70 years old   ■ Aged ≥ 70 years old

Frequency of missed doses
(% respondents treated with tablets)

	Aged < 70 years old	Aged ≥ 70 years old
Never	70%	82%
Less than once a month	18%	18%
1-2 times per month	8%	
3-5 times a month	3%	
6 or more times per month		

■ Never
■ Less than once a month
■ 1-2 times per month
■ 3-5 times a month
■ 6 or more times per month

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

Preferred administration route (hypothetical)
(% all respondents)

Tablet only

Infusion only

Injection only

Any combination

70%

6%

5%

19%

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%**

Base: Respondents with each treatment experience (All n=247; Younger patients n=194; Older patients n=53) - Q4b - See note section

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

*Includes patients who stated their treatment as 'Other'

Base: Respondents with each treatment experience (All n=247; Treated n=137; Latest treatment with tablet n=74; Latest treatment without tablet n=44) - Q4b - See note section

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

I wouldn't need to travel to the hospital so often	48%
Tablets are less restrictive – I would not be attached to a drip	34%
I only have to take a pill, there are no needles involved	29%
Tablets would be less of a burden on my family and friends	16%
It's recommended by my doctor	13%

Patients do not seem very concerned about seeing their doctor/nurse less regularly

Base: Respondents who would prefer tablet only treatment (n=172) - Q6
See note section for details
See Appendix for more information
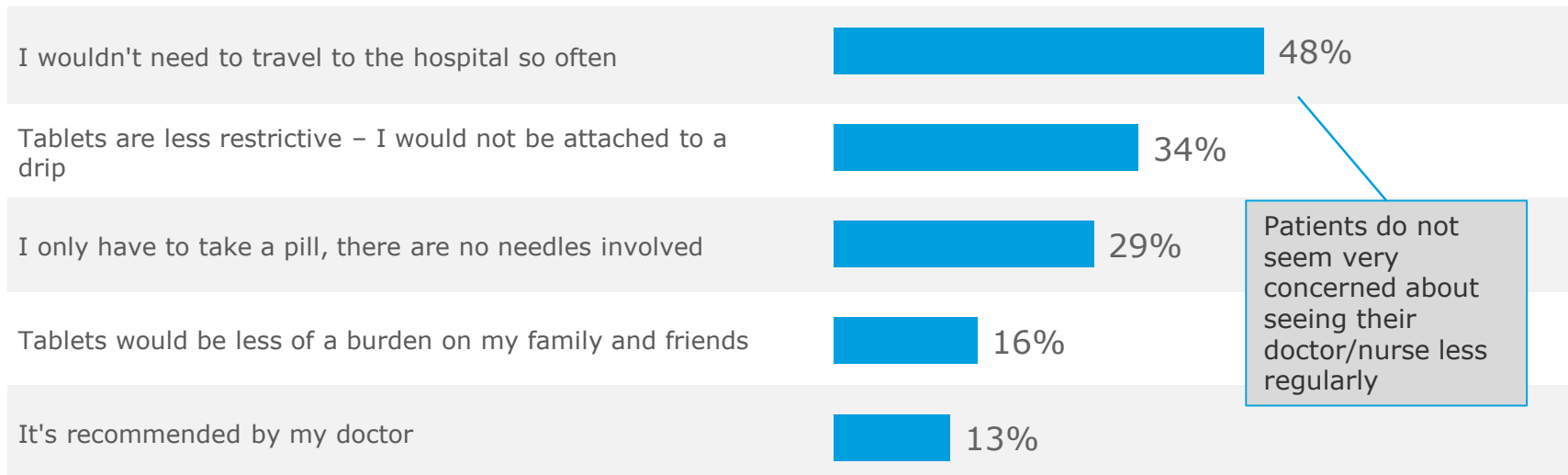
....Particularly amongst younger patients

70%

Key reasons for hypothetical preference <u>by age group</u>: tablet only
(% respondents who would prefer tablet-only treatment)
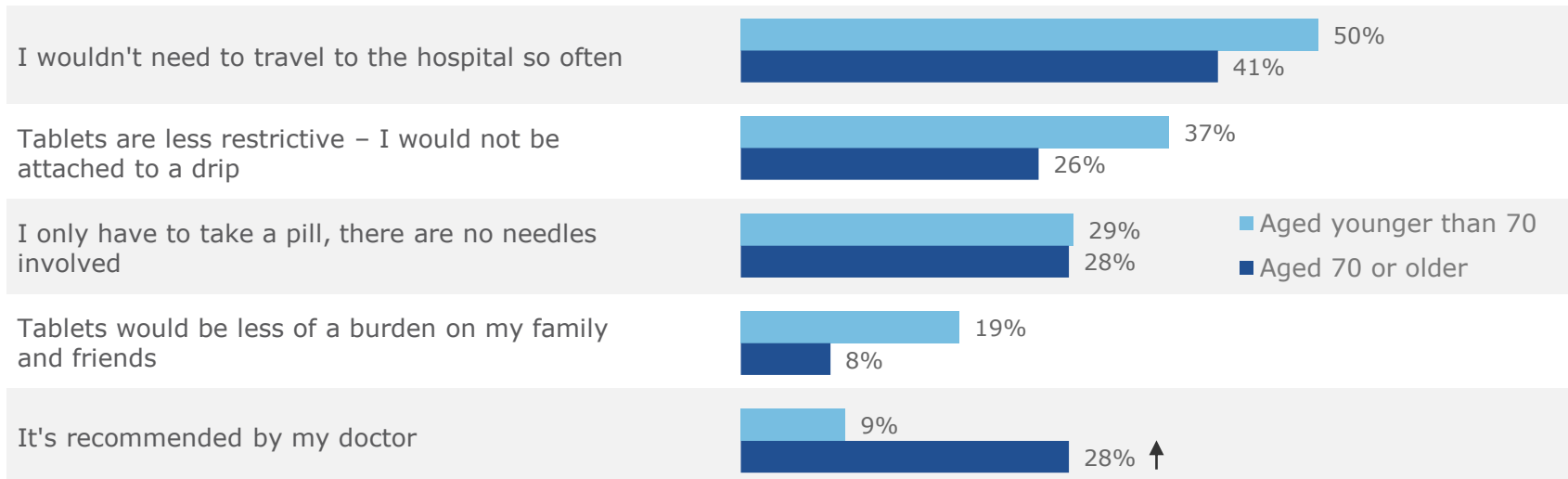Respondents selected their <u>Top 2</u> reasons

I wouldn't need to travel to the hospital so often	50% / 41%
Tablets are less restrictive – I would not be attached to a drip	37% / 26%
I only have to take a pill, there are no needles involved	29% / 28%
Tablets would be less of a burden on my family and friends	19% / 8%
It's recommended by my doctor	9% / 28% ↑

■ Aged younger than 70
■ Aged 70 or older

↑ Significantly higher than other group

Primary reasons for infusion/injection preference are a little more mixed
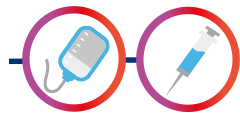
11%

Key reasons for hypothetical preference: infusion or injection only
(% respondents who would prefer infusion or injection only treatment)
Respondents selected their <u>Top 2</u> reasons

I would take my treatment at a fixed time	30%
It means I would have regular contact with my doctor/nurse	26%
I think I would suffer fewer side effects	22%
It seems like a stronger treatment	22%
I wouldn't have to remember to take my treatment everyday	19%
I would only receive the treatment for a fixed period of time (I wouldn't have to receive it forever)	19%

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
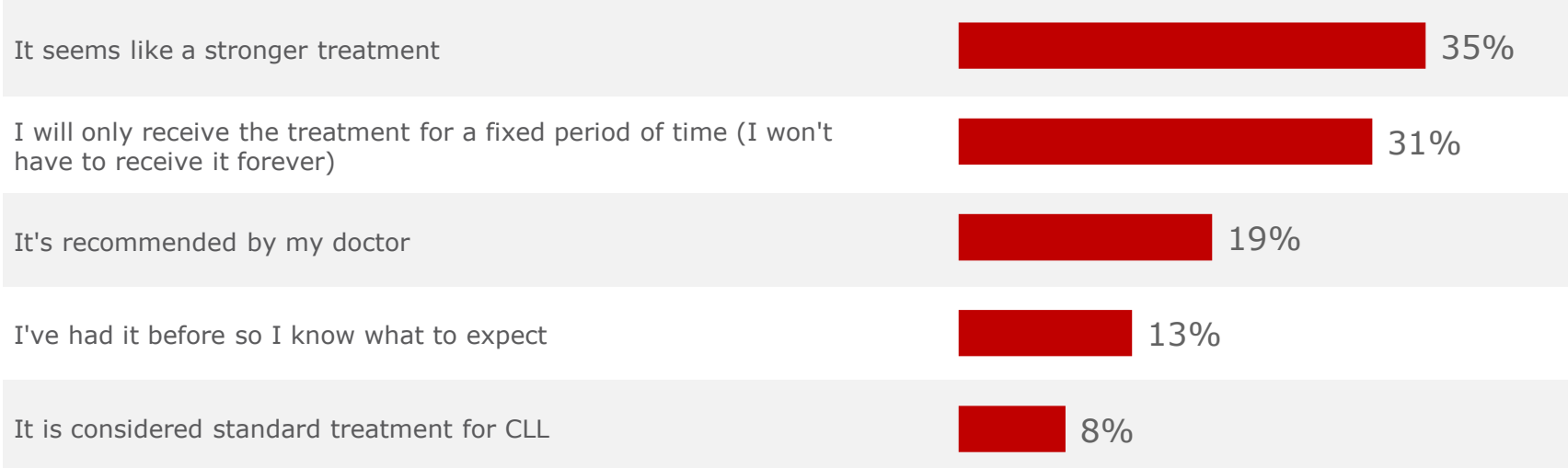
19%

Key reasons for hypothetical preference: combination
(% respondents who would prefer combination treatment)
Respondents selected their Top 2 reasons

It seems like a stronger treatment	35%
I will only receive the treatment for a fixed period of time (I won't have to receive it forever)	31%
It's recommended by my doctor	19%
I've had it before so I know what to expect	13%
It is considered standard treatment for CLL	8%

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)

Treatment offering long-term remission	71%
My quality of life while taking the treatment	54%
How long it enables you to live	49%
Length of time with no progression of disease	40%
Risk of side effects	34%
I want to avoid chemotherapy	27%
The proportion of patients whose cancer shrinks/disappears	20%
How long I have to take the treatment	6%

Treatment duration is **not** a key driver.
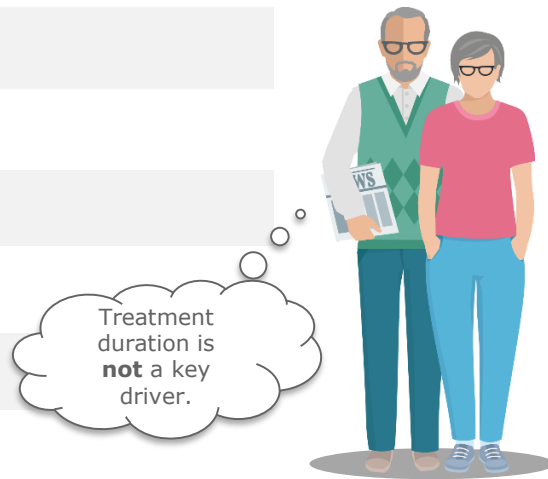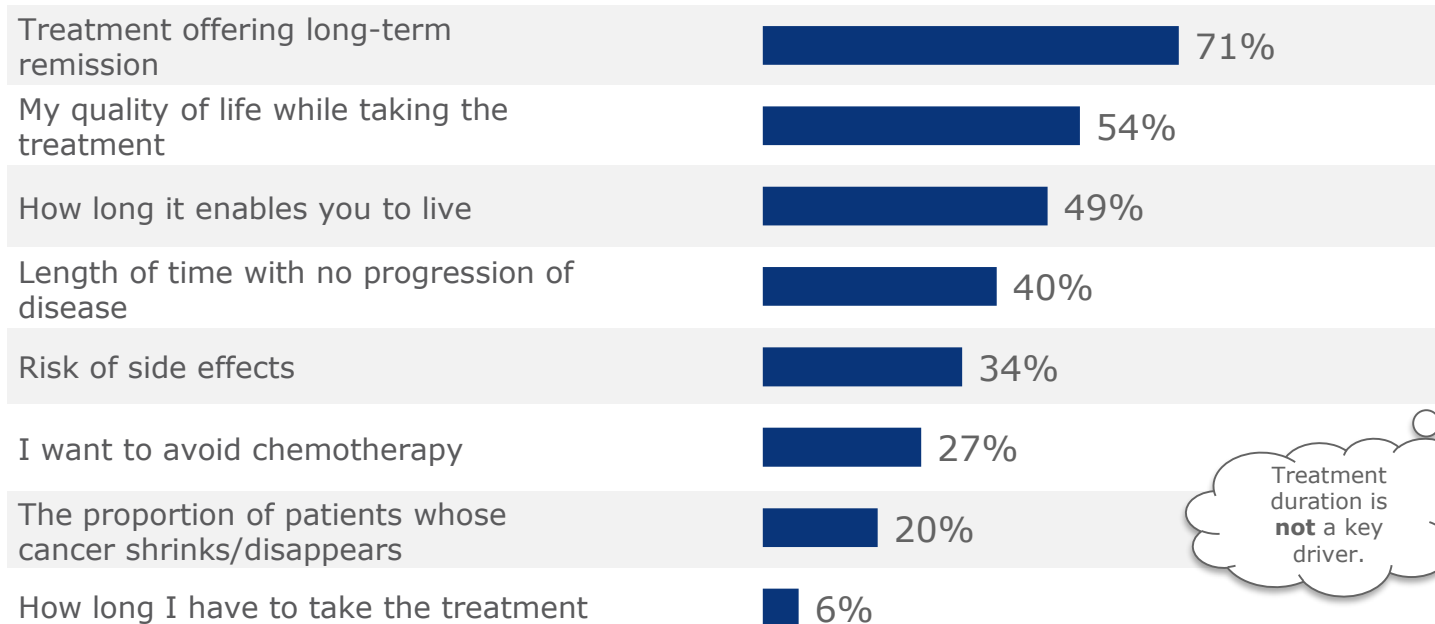
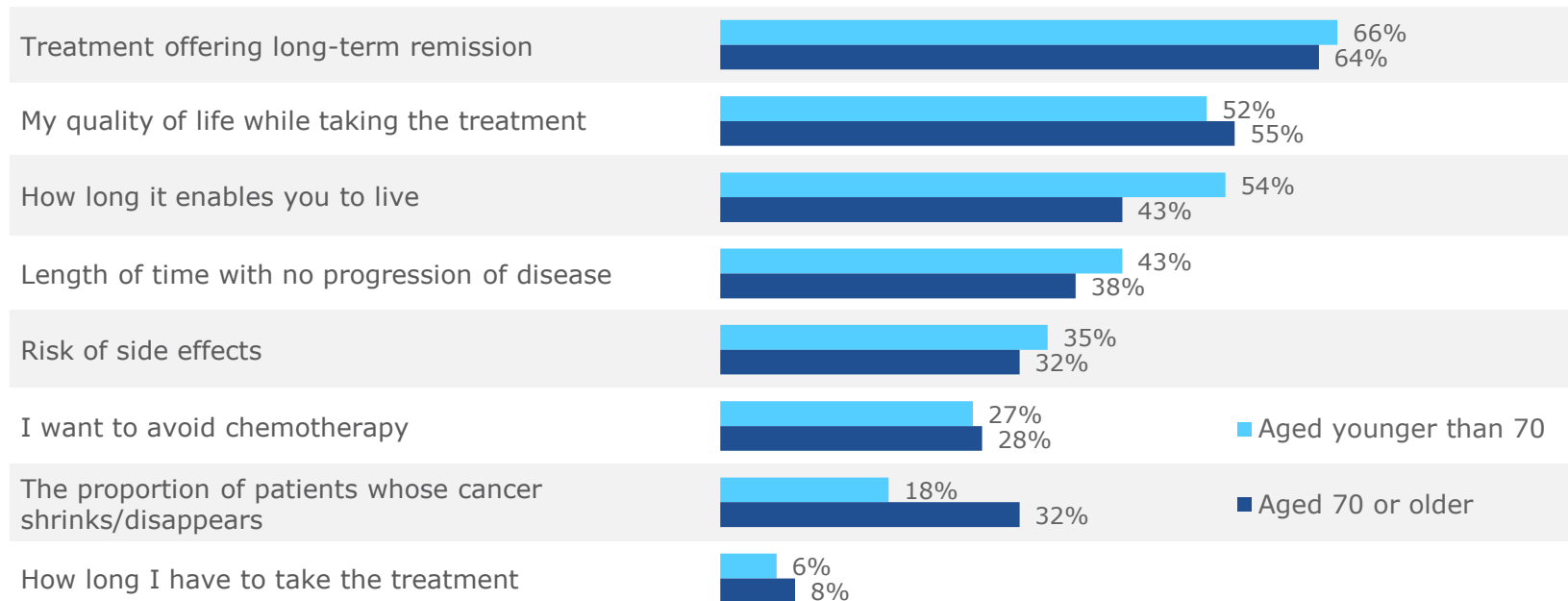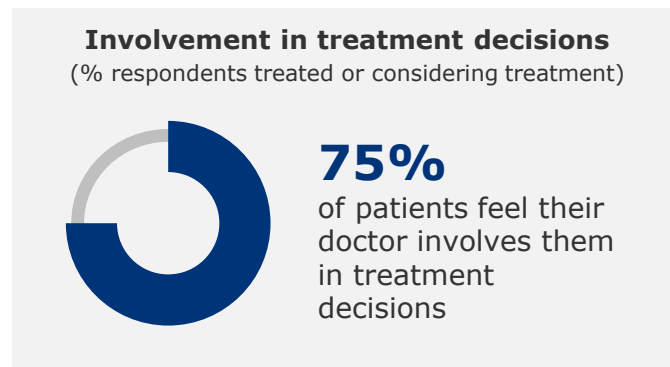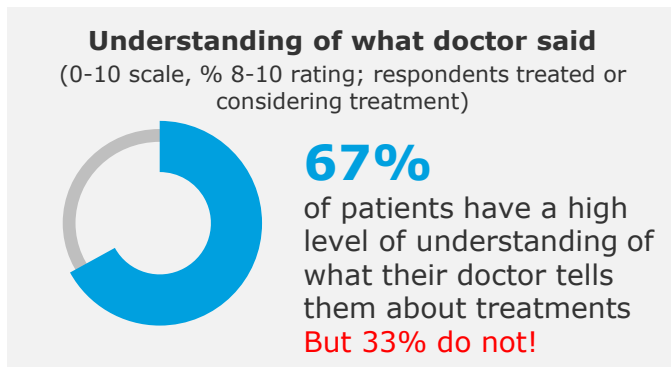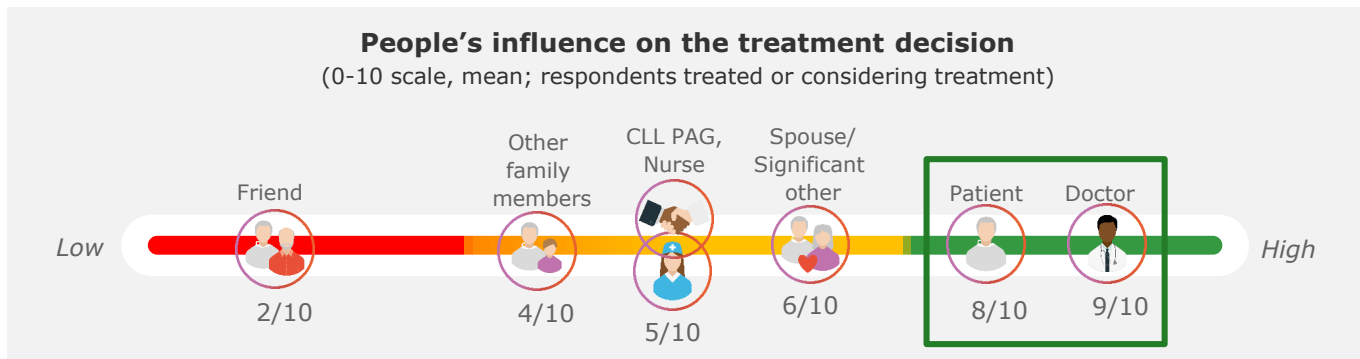# Younger patients are more influenced than older patients by how long a treatment will enable them to live

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

Criteria	Aged younger than 70	Aged 70 or older
Treatment offering long-term remission	66%	64%
My quality of life while taking the treatment	52%	55%
How long it enables you to live	54%	43%
Length of time with no progression of disease	43%	38%
Risk of side effects	35%	32%
I want to avoid chemotherapy	27%	28%
The proportion of patients whose cancer shrinks/disappears	18%	32%
How long I have to take the treatment	6%	8%

■ Aged younger than 70
■ Aged 70 or older

Base: Respondents who have received a treatment or are considering their first treatment (n=149) – Q11
See note section for details, including exact wording of answer codes

Patients are active participants in treatment decisions

People's influence on the treatment decision
(0-10 scale, mean; respondents treated or considering treatment)

Low ——————— High

- Friend — 2/10
- Other family members — 4/10
- CLL PAG, Nurse — 5/10
- Spouse/Significant other — 6/10
- Patient — 8/10
- Doctor — 9/10

Understanding of what doctor said
(0-10 scale, % 8-10 rating; respondents treated or considering treatment)

67% of patients have a high level of understanding of what their doctor tells them about treatments
But 33% do not!

Involvement in treatment decisions
(% respondents treated or considering treatment)

75% of patients feel their doctor involves them in treatment decisions

Base: Respondents who have received a treatment or are considering their first treatment (n=149) - Q12, Q14, Q16
See note section for details
See Appendix for more information

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

Clarity of treatment explanations by doctor
(% respondents treated or considering treatment)

26%

74%
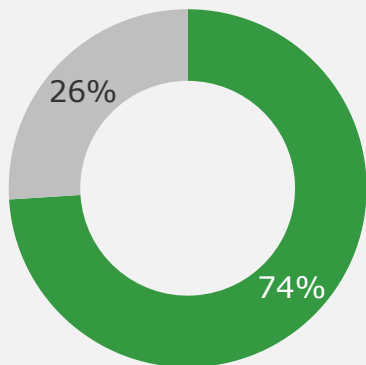
■ My doctor explained the different treatments clearly (including pros and cons of each)

Understanding of what doctor said when discussing treatments
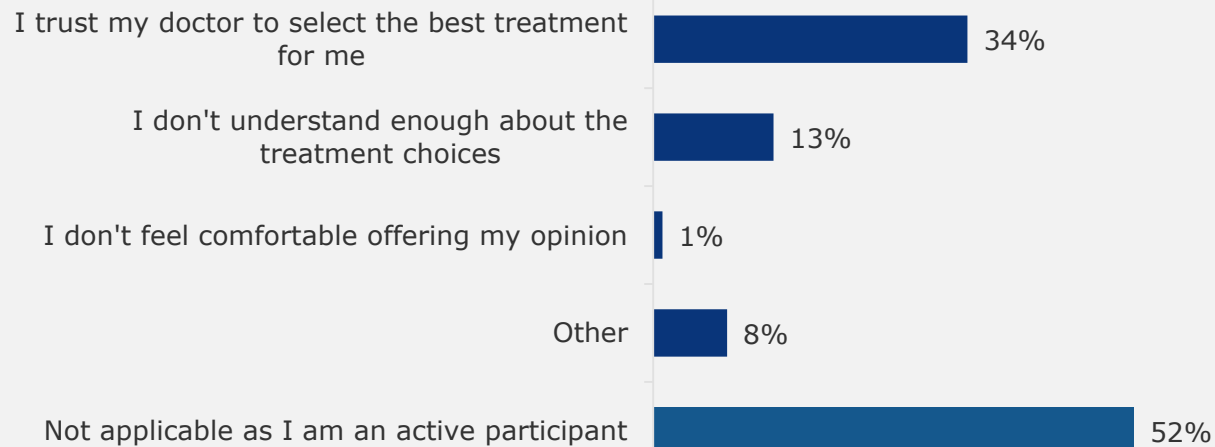(0-10 scale, % respondents treated or considering treatment)

67%

26%

7%

Mean 7.7

Low level of understanding (0-2 out of 10)

High level of understanding (8-10 out of 10)
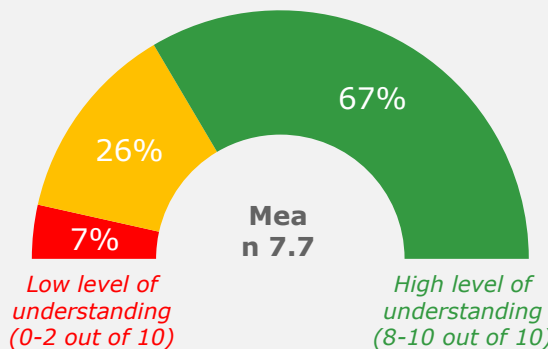
91% of those who say their doctor explained different treatments clearly feel their doctor involves them in treatment decisions

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)

Reason	Percentage
I trust my doctor to select the best treatment for me	34%
I don't understand enough about the treatment choices	13%
I don't feel comfortable offering my opinion	1%
Other	8%
Not applicable as I am an active participant	52%

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)

Reason	%
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%

Many patients are worried about their CLL symptoms returning

Worries about symptoms returning
(0-10 scale; % all respondents)

Not at all worried (0-2 out of 10) — 14%

42%

44% — *Extremely worried (8-10 out of 10)*

Mean 6.5
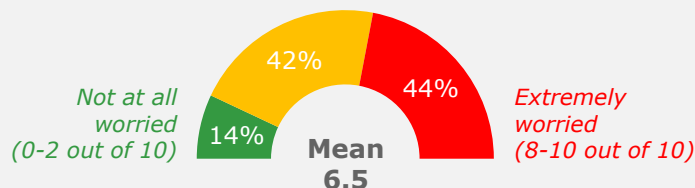
➡ **CLL patients in EU4 and CEE are significantly more worried about symptoms returning**

	Not at all worried	Extremely 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	Extremely 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

Base: All respondents (n=247) - Q22
See note section for details

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

Adherence level on tablet treatment
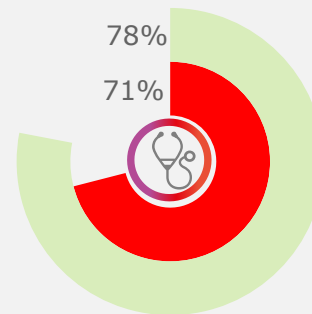(% respondents treated with tablet who have <u>never</u> missed a dose)

65%

78%
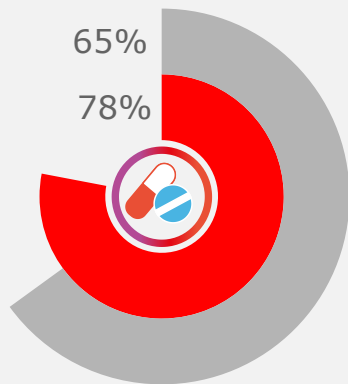
Lower level of worry (0-7 out of 10)
High level of worry (8-10 out of 10)

Involvement in treatment decisions
(% respondents treated or considering treatment who feel their doctor involves them in decisions)
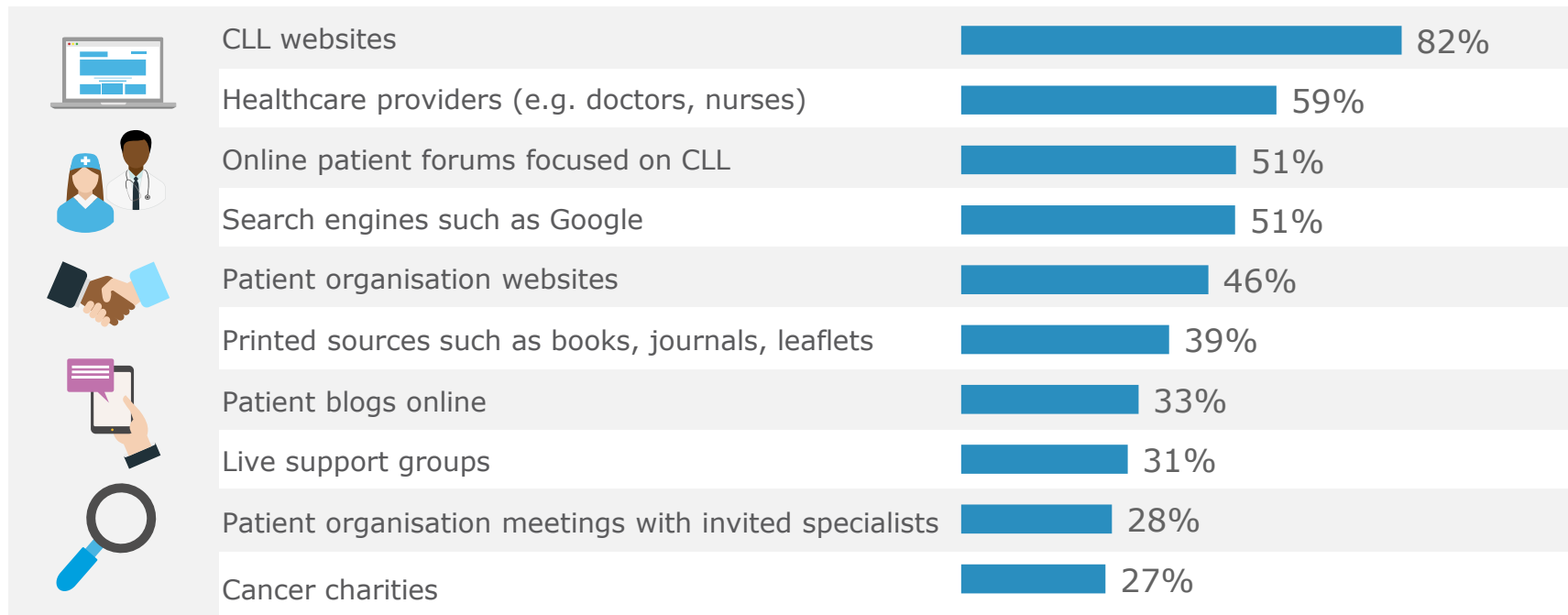
78%

71%

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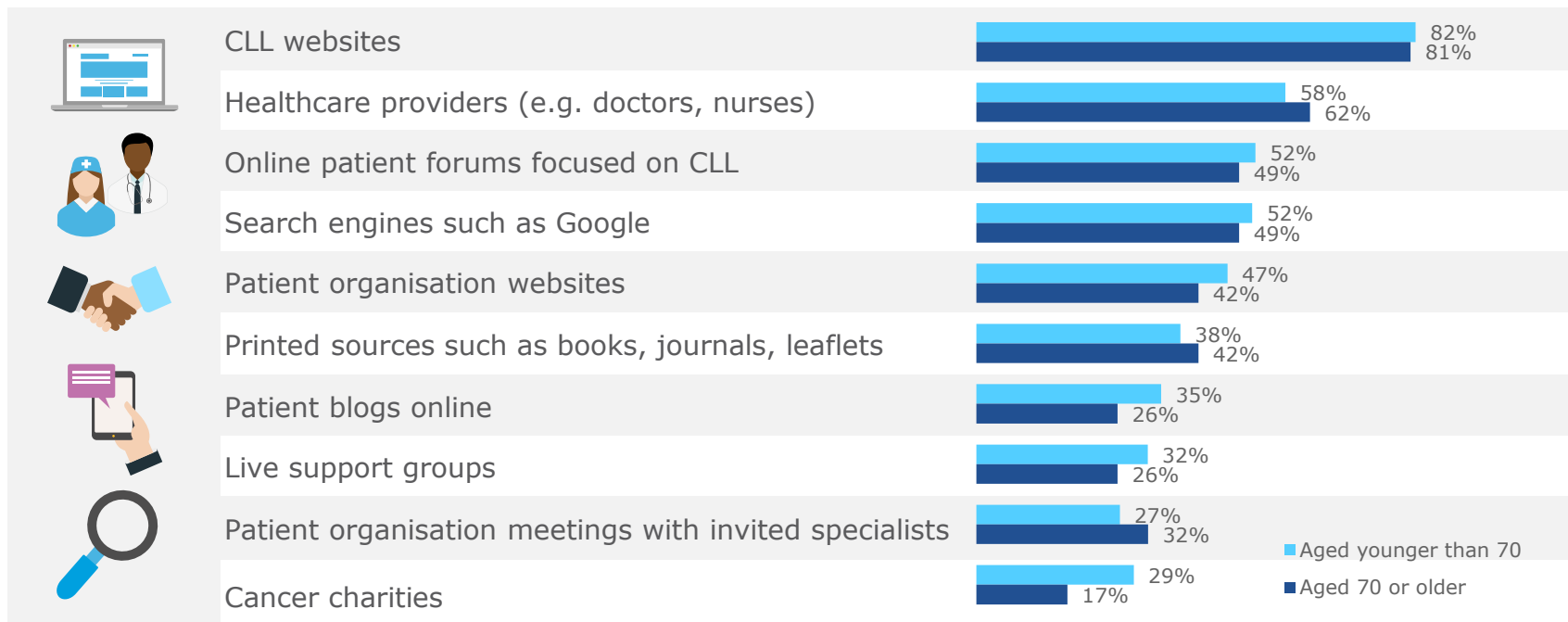
Top 10 sources of information for CLL
(% all respondents)

Source	%
CLL websites	82%
Healthcare providers (e.g. doctors, nurses)	59%
Online patient forums focused on CLL	51%
Search engines such as Google	51%
Patient organisation websites	46%
Printed sources such as books, journals, leaflets	39%
Patient blogs online	33%
Live support groups	31%
Patient organisation meetings with invited specialists	28%
Cancer charities	27%

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

Both younger and older patients rely on CLL websites for information

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

Source	Aged younger than 70	Aged 70 or older
CLL websites	82%	81%
Healthcare providers (e.g. doctors, nurses)	58%	62%
Online patient forums focused on CLL	52%	49%
Search engines such as Google	52%	49%
Patient organisation websites	47%	42%
Printed sources such as books, journals, leaflets	38%	42%
Patient blogs online	35%	26%
Live support groups	32%	26%
Patient organisation meetings with invited specialists	27%	32%
Cancer charities	29%	17%

■ Aged younger than 70
■ Aged 70 or older

Base: All respondents (All n=247: Respondents younger than 70 n=194; Respondents aged 70 or older n=53) - Q21 - See note section for details

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 FORINFORMATION

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.
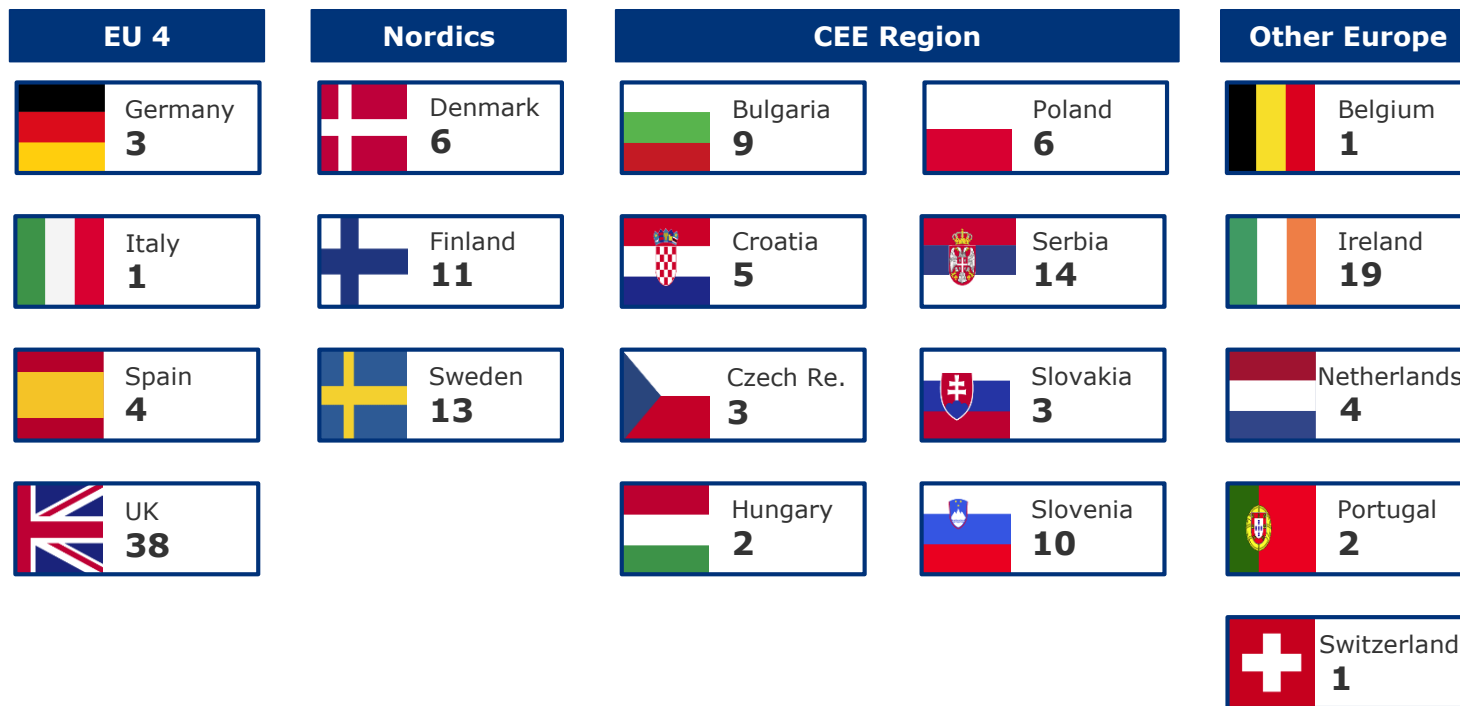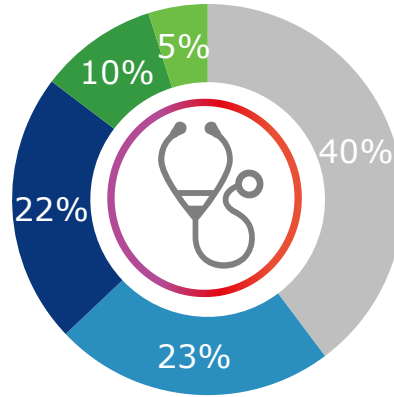
TREATMENT SATISFACTION IS HIGH

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

Appendix

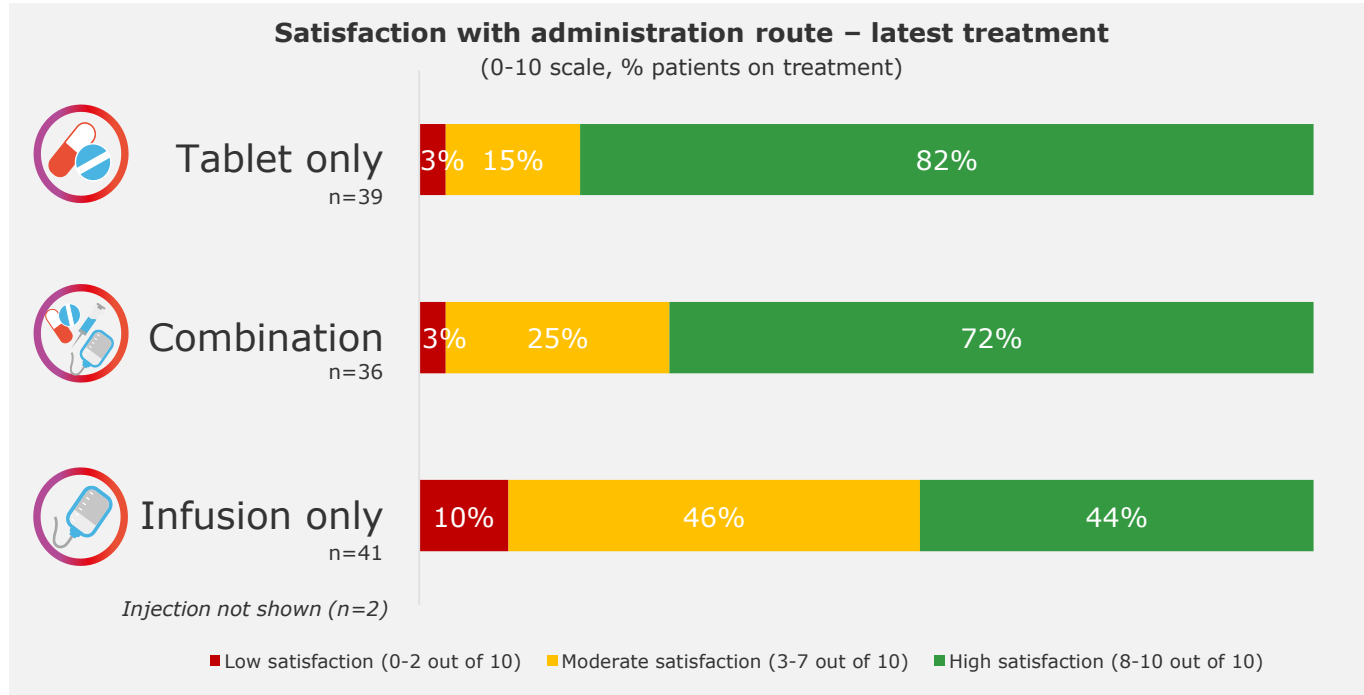# A total of 155 CLL patients from across Europe participated

EU 4

Germany	**3**
Italy	**1**
Spain	**4**
UK	**38**

Nordics

Denmark	**6**
Finland	**11**
Sweden	**13**

CEE Region

Bulgaria	**9**		Poland	**6**
Croatia	**5**		Serbia	**14**
Czech Re.	**3**		Slovakia	**3**
Hungary	**2**		Slovenia	**10**

Other Europe

Belgium	**1**
Ireland	**19**
Netherlands	**4**
Portugal	**2**
Switzerland	**1**

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

40%

23%

22%

10%

5%

- 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

Satisfaction with administration route – latest treatment
(0-10 scale, % patients on treatment)

Tablet only n=39
- 3%
- 15%
- 82%

Combination n=36
- 3%
- 25%
- 72%

Infusion only n=41
- 10%
- 46%
- 44%

Injection not shown (n=2)

■ Low satisfaction (0-2 out of 10) ■ Moderate satisfaction (3-7 out of 10) ■ High satisfaction (8-10 out of 10)

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 <u>Top 2</u> reasons

I wouldn't need to travel to the hospital so often
- 36%
- 45%
- 57%

Tablets are less restrictive – I would not be attached to a drip
- 27%
- 30%
- 29%

I only have to take a pill, there are no needles involved
- 27%
- 40%
- 33%

Tablets would be less of a burden on my family and friends
- 18%
- 10%
- 10%

It's recommended by my doctor
- 36%
- 15%
- 12%

Legend:
- Received tablet only
- Received infusion only
- Received combination
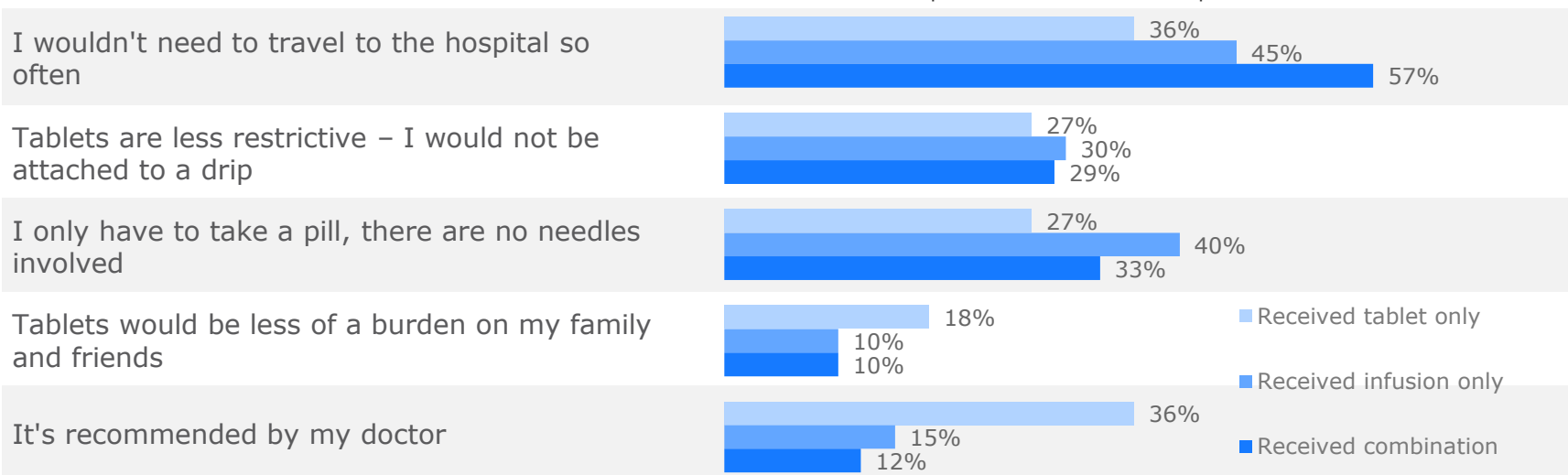
Injection not shown (n=2)

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)

	% to select item as a Top 2 reason	% to select item as a reason
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%

Base: All respondents who would prefer tablet only treatment (n=172) – Q5, Q6 – See note section for details

Key reasons for hypothetical preference: infusion or injection only

	% to select item as a Top 2 reason	% to select item as a reason
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)

	% to select item as a Top 2 reason	% to select item as a reason
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%

Base: All respondents who would prefer combination treatment (n=48) – Q8a, Q8b – See note section for details

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

Top 3 criteria in treatment decisions <u>by treatment preference</u>
(% respondents treated or considering treatment)

Criteria	Tablet	Infusion/Injection (NET)	Combination
Treatment offering long-term remission	71%	76%	65%
My quality of life while taking the treatment	57%	59%	42%
How long it enables you to live	53%	35%	42%
Length of time with no progression of disease	38%	41%	46%
Risk of side effects	33%	35%	38%
I want to avoid chemotherapy	26%	18%	35%
The proportion of patients whose cancer shrinks/disappears	19%	29%	15%
How long I have to take the treatment	4%	6%	15%

■ Tablet
■ Infusion/Injection (NET)
■ Combination

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

Top 3 criteria in treatment decisions <u>by treatment experience</u>
(% treated respondents)

Criteria	Tablet only	Infusion only	Combination
Treatment offering long-term remission	46%	67%	81%
My quality of life while taking the treatment	69%	64%	51%
How long it enables you to live	23%	46%	53%
Length of time with no progression of disease	54%	30%	44%
Risk of side effects	39%	46%	27%
I want to avoid chemotherapy	31%	21%	23%
The proportion of patients whose cancer shrinks/disappears	23%	18%	19%
How long I have to take the treatment	15%	9%	1%

- Tablet only
- Infusion only
- Combination

Injection not shown (n=2)

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

15%	23%	62%

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

18%	33%	49%

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

People's influence on the treatment decision
(0-10 scale, mean; respondents treated or considering treatment)

Doctor
91%
8%
Mean 9.2

Patient
64%
28%
8%
Mean 7.6

Spouse/ Significant other
32%
32%
22%
14%
Mean 5.7

Nurse
31%
23%
28%
18%
Mean 4.8

CLL PAG
35%
21%
28%
16%
Mean 4.7

Other family members
30%
13%
41%
16%
Mean 3.7

Friend
22%
5%
51%
22%
Mean 2.3

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

Moderate level of influence
(3-7 out of 10)

Low level of influence
(0-2 out of 10)

Not applicable

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	
CLL Patient Advocacy Group	5	5		5	5	***Moderate** level of influence (3-7 out of 10)*
Nurse	5	5		5	4	
Other family members	4	3		4	4	
Friend	2	2		2	3	***Low** level of influence (0-2 out of 10)*

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
Patient	7	7	6	9	9
Spouse/ Significant other	5	6	5	6	6
CLL Patient Advocacy Group	4	5	1	5	6
Nurse	6	5	4	5	4
Other family members	3	5	4	5	3
Friend	2	3	1	3	2

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

Moderate level of influence (3-7 out of 10)

Low level of influence (0-2 out of 10)

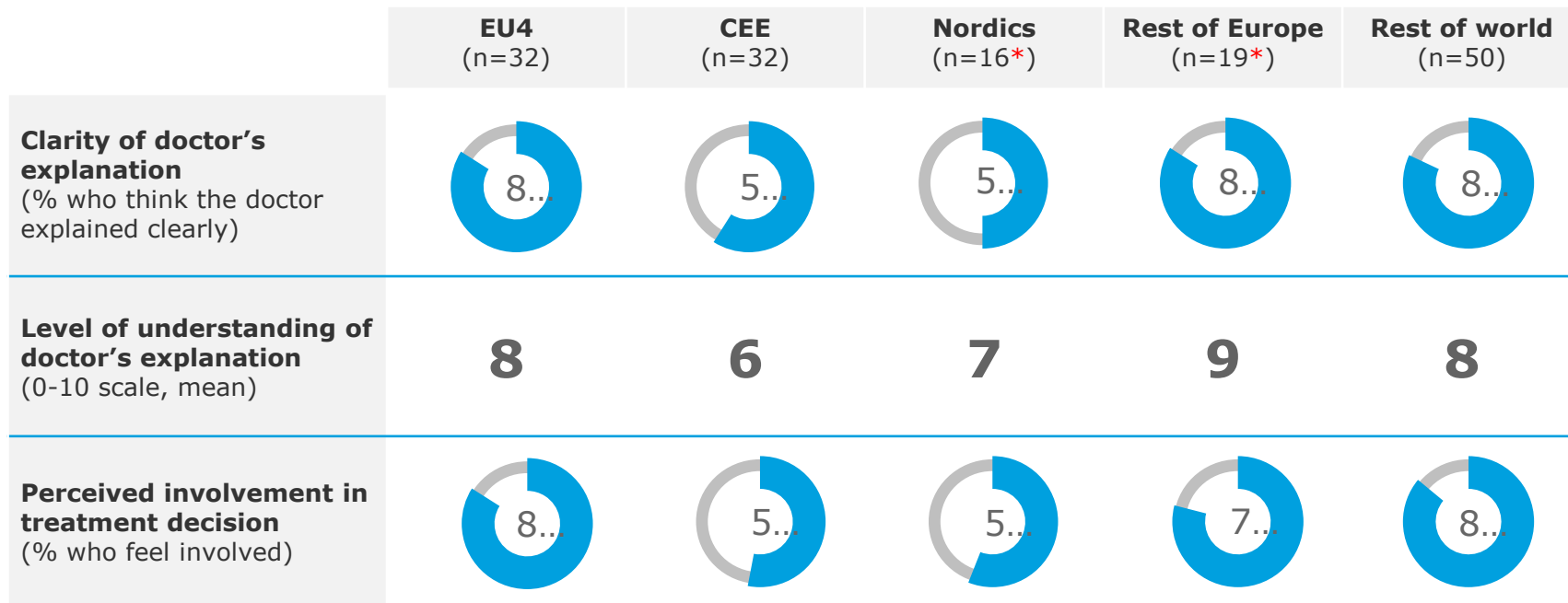Base: Respondents who have received a treatment or are considering their first treatment per region (n=149) - Q12
See note section for details
* CAUTION: LOW BASE

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)

	EU4 (n=32)	CEE (n=32)	Nordics (n=16*)	Rest of Europe (n=19*)	Rest of world (n=50)
Clarity of doctor's explanation (% who think the doctor explained clearly)	8...	5...	5...	8...	8...
Level of understanding of doctor's explanation (0-10 scale, mean)	8	6	7	9	8
Perceived involvement in treatment decision (% who feel involved)	8...	5...	5...	7...	8...

Base: Respondents who have received a treatment or are considering their first treatment per region (n=149) - Q13, Q14, Q16
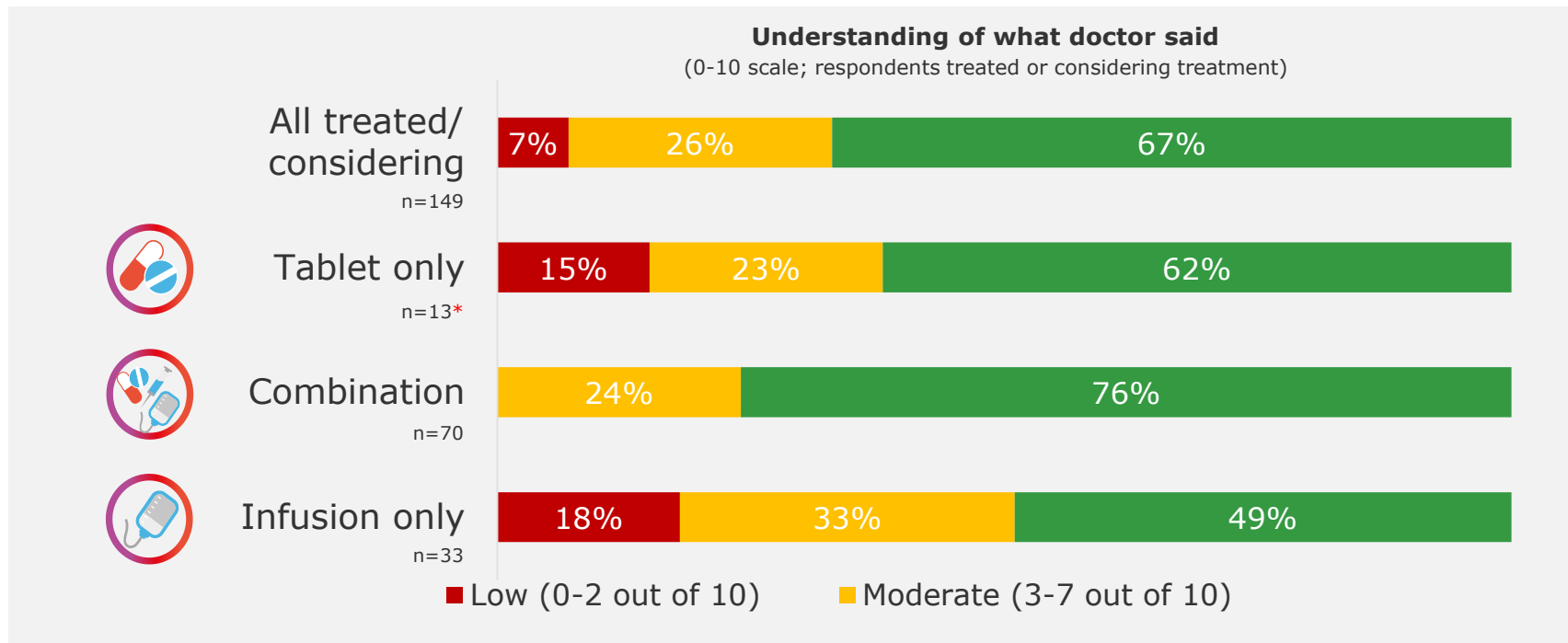- See note section for details
* CAUTION: LOW BASE

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)	7…	8…	7…	7…
Level of understanding of doctor's explanation (0-10 scale, mean)	**8**	**8**	**8**	**8**
Perceived involvement in treatment decision (% who feel involved)	7…	7…	7…	7…

Patients who have received any treatment combination understand their doctors best

Understanding of what doctor said
(0-10 scale; respondents treated or considering treatment)

Group	Low (0-2)	Moderate (3-7)	High
All treated/considering (n=149)	7%	26%	67%
Tablet only (n=13*)	15%	23%	62%
Combination (n=70)		24%	76%
Infusion only (n=33)	18%	33%	49%

■ Low (0-2 out of 10)   ■ Moderate (3-7 out of 10)

Patients who have received any combination feel most involved in treatment decisions
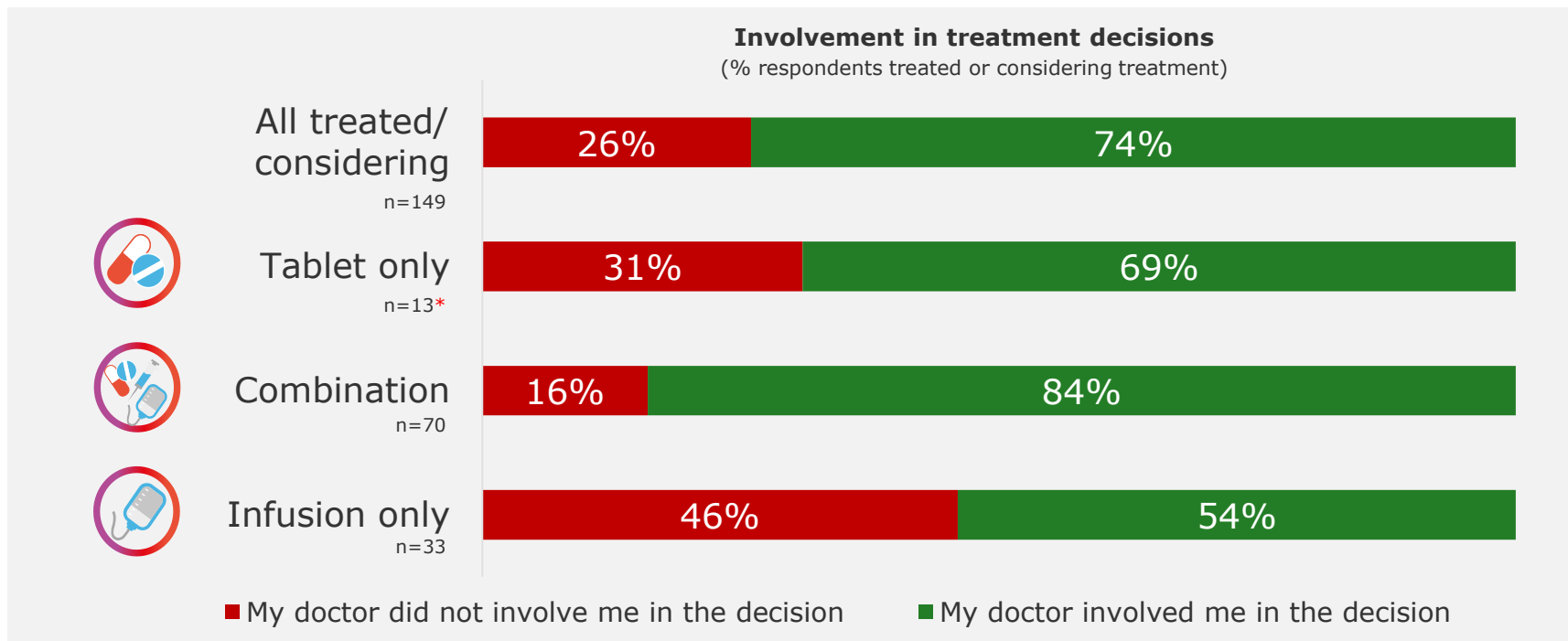
Involvement in treatment decisions
(% respondents treated or considering treatment)

	My doctor did not involve me in the decision	My doctor involved me in the decision
All treated/considering n=149	26%	74%
Tablet only n=13*	31%	69%
Combination n=70	16%	84%
Infusion only n=33	46%	54%

■ My doctor did not involve me in the decision ■ My doctor involved me in the decision

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%
Healthcare providers (e.g. doctors, nurses)	57%	58%	73%	52%	58%
Online patient forums focused on CLL	54%	37%	50%	33%	64%
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%
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%

High usage (70-100%)

Moderate usage (30-69%)

Low usage (0-29%)

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)

Source	%
Dr. Brian Koffman's CLL Society website	23%
Email	19%
Facebook advertisement	15%
My patient support group/organization	14%
Social media	13%
Patient support group website	9%
A friend	3%
My doctor	2%
Other	3%

Base: All respondents (n=247) - Q24
See note section for details