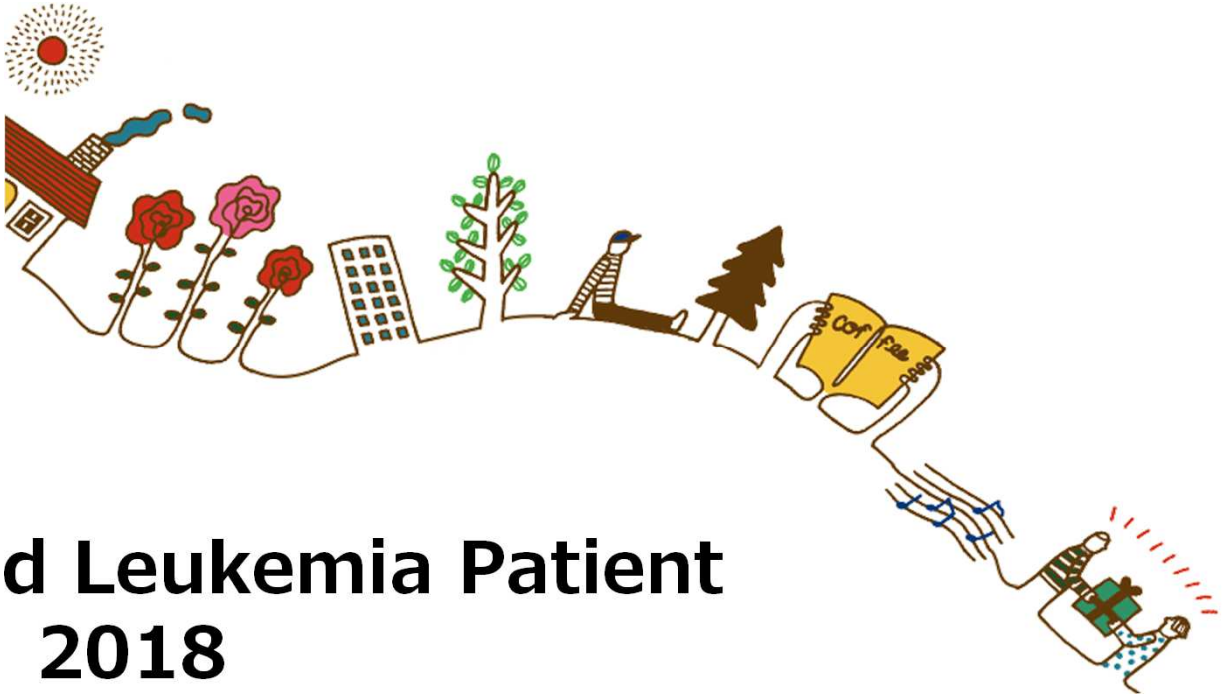


Chronic Myeloid Leukemia Patient Survey Report 2018

IZUMI Japan

JUNE 2018

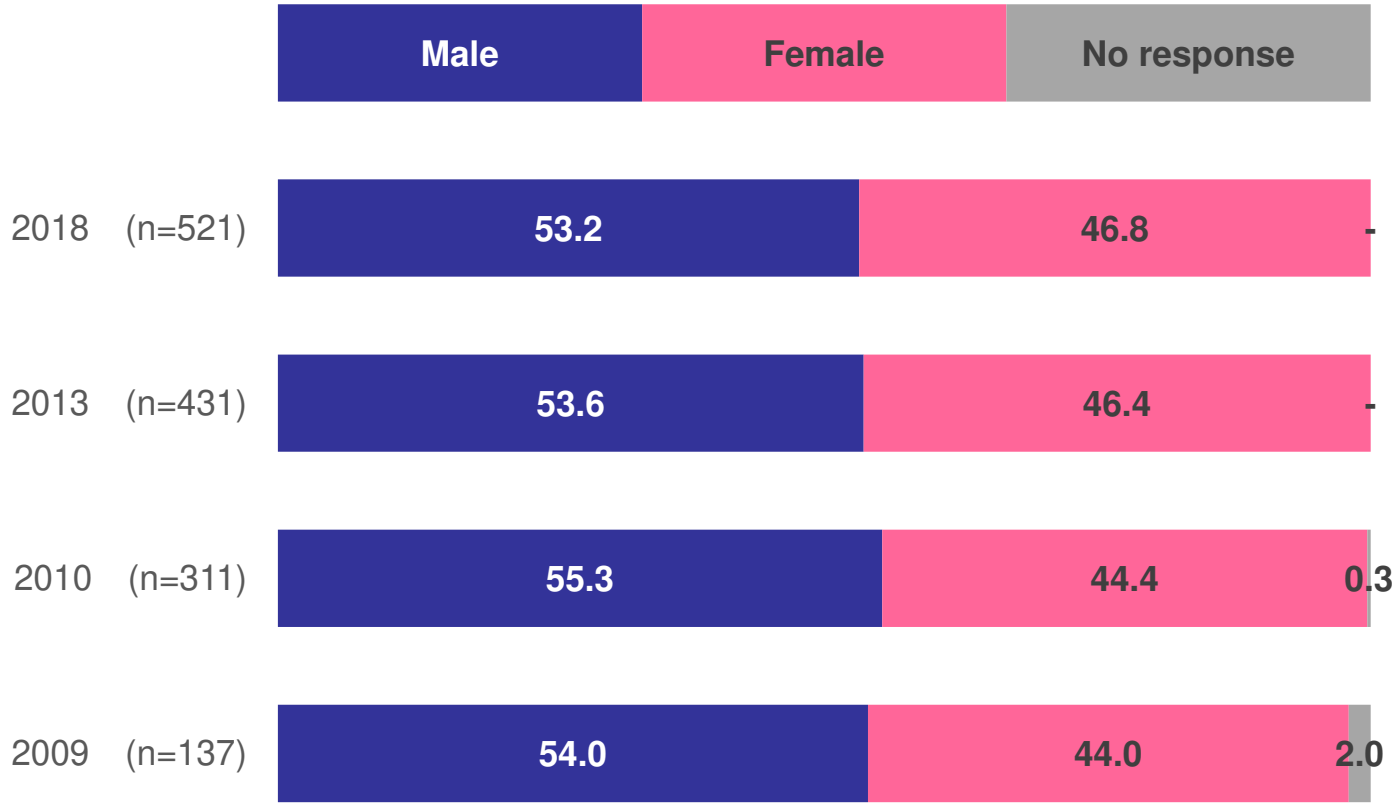
Nobody's Unpredictable

Survey Design

Purpose:	To understand the daily concerns and difficulties for patients with chronic myeloid leukemia (CML) regarding treatments. Gather data regarding drug change status and use of High-cost Medical Expense benefit to offer updated data for medical providers, pharmaceutical firms and patients and their families to improve CML treatment.
Research firm:	Ipsos Marketing (A third-party research firm was used to ensure validity of data)
Location:	Japan (nationwide)
Method:	Survey by mail
Study population:	Members of “Izumi” (Association of patients with CML and their families)
Sample selection:	‘Izumi’ member list
Response Collection:	Number of samples=806, Number of Responses=544 (Response rate=67.5%) Valid responses=521(Valid response rate=64.6%) Invalid responses 23,(Reason=Incomplete response=13) Response returned after response collection deadline=6) Reject =1 Not available=3
Survey period:	Late May 2018 to Mid June 2018

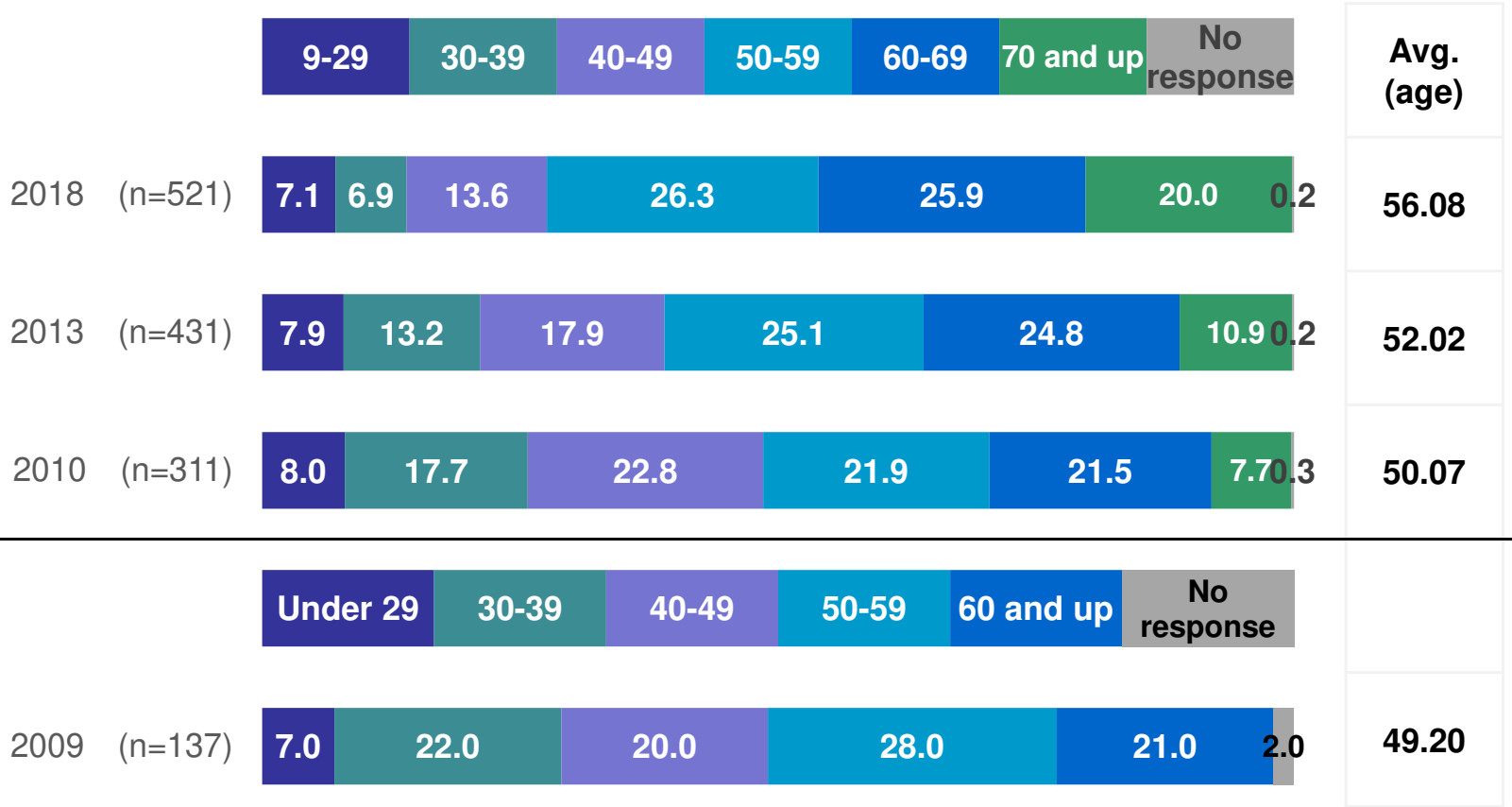
Patient Gender

- Patient gender: Male 53%, Female 47%. This ratio has only marginally changed since the first survey in 2009.



Patient Age

- Patients are aging.
- Patients by age groups “50s=26%”, “60s=26%”, “70 and up=20%”
  In the last survey, the main age groups were 50s and 60s. The “70 and up” group was 10.9%. In this survey, the “70 and up” group nearly doubled, and the average age increased by more than 4 years.



Note: In 2010, the youngest age group was ”5-29 yrs” and “4-29 yrs” in the 2013 survey

Current symptoms and the treatment progress(1/2)

●Inconvenient and difficult issues while continuing treatment

- Top concern is “Future prospects (issues related to treatment such as developing drug resistance and possible recurrence)” (67%), followed by “Future prospects (whether or not to be able to continue working, studying and child rearing as before)” (32%). Other concerns are “Do not know where to obtain information” (20%), “Unsure about ability to go out with friends and enjoy exercise and have times for hobbies” (17%), and “Do not know if it’s better to change to a new drug” (16%).

●Difficulties in family life

- Economic difficulties dominate: “Burden of medical expenses related to the treatment” (68%) is the top concern, followed by “Decreased income due to illness” (14%). After that, “Finding work”(9%), “Family care” (7%), “Childbirth” (7%), “Child rearing” (6%), and “Marriage” (5%) are mentioned.
- Difficulties in family life have only minimally changed from the past two surveys. The new result shows a slight declining trend in difficulties on “Decreased income due to illness,” “Childbirth,” and “Marriage.”

●Satisfaction with life in general (Scale of 10 points with 10 being the most satisfied)

- 27% of patients give scores of “9-10 points” (Top 2), which indicate very satisfied. 50% rated “8-10 points” (Top 3), which suggests relatively high satisfaction. In contrast, “1-2 points” (Bottom 2) with very low satisfaction is 3%, and “1-3 points,” which suggests generally low satisfaction (Bottom 3) is 7%. The average satisfaction score is 7.10.
- In the last survey, Top 2 was 20%, and Top 3 was 48%. The latest survey shows better results than previous surveys, which indicate patient satisfaction in overall life has improved.

Current symptoms and the treatment progress(1/2)

●CML history and hospital visit interval

➢ 38% of patients have “10 years or longer” CML history. “5-8 years” is 20%, and “8-less than 10 years” is 17%. Average CML history is 7.3 years. Regarding the interval between hospital visits, nearly half of the patients (47%) said “12 weeks or more.” “8-less than 9 weeks” and “10-less than 11 weeks” combined account for as high as 27%. Average interval is 10.2 weeks.

➢ In this survey, patients with “8 years or longer” CML history are 55%, which is more than 30 points up from the previous survey. The average history has increased by 1.8 years to 7.3 years. Regarding the average of hospital visit interval, the time is definitely longer since it was 9.0 week in the survey and 7.1 weeks before that.

● Recent bothersome symptoms (overall)

➢ The most bothersome symptom is “muscle cramp” (33%), followed by “fatigue” (33%), “increase of gray hair” (23%), “swelling” (23%), and “skin turns pale” (18%). While common symptoms are the same as the previous two surveys, the percentages of complaints clearly decreased due to availability of the variety of drugs.

● Recent bothersome symptoms (by drug)

➢ Gleevec: muscle cramp (68.5%), skin turns pale (35.6%), swelling (35.6%), and hyposphagma (30.2%)
➢ Tasigna: fatigue (30.9%), muscle cramp (30%), skin rash (22.7%), muscle ache (17.3%), and cholesterol (17.3%)
➢ Sprycel: increase of gray hair (34.5%), fatigue (30.3%), swelling (26.8%), and pleural effusion (21.2%)
➢ Bosulif: diarrhea (45.5%), skin rash (36.4%), fatigue (21.2%), and pleural effusion (21.2%)

●Recent treatment response stage

➢ The most common response stage is “Complete Molecular Response (MR4.5)” with 21%, followed by “Complete Molecular Response” with 17%, “Major Molecular Response (MMR)” with 12%, and “Complete Molecular Response (MR4.5) “ with 12%.

➢ In the previous survey, a newly introduced stage called “Major Molecular Response (MMR)” accounted for a high percentage. However, in the new survey, because classification of stage is further subdivided, it is difficult to make a comparison. Approximately 24% of the responses are in the “Unknown/do not know” stage, increased by 6 points from the previous survey. This suggests an increased number of patients who do not know their current response stage.

Current symptoms and the treatment progress(2/2)

- Recent treatment method
  - 29% of respondents said “taking Gleevec”, which makes it the most common treatment method. However, use of Gleevec is significantly decreased compared with the survey in 2013 (48%) and in 2010 (78%). The second common drug is Sprycel (28%), followed by Tasigna (21%), and Bosulif (6%).
  - Compared with the previous survey, use of Gleevec has significantly decreased as noted above. The new drug, Bosulif, is added in this survey and “Participation in the stopping medication clinical trial” increased by 6 points.
  - Most common daily dose of Gleevec is 400mg (52%), followed by 300mg (26%). Taking a 50mg daily dose of Sprycel is 35%, which is double from the last survey result. In the last survey, 100mg was the most common daily dose for Sprycel, but this is half in the new survey. For Tasigna, 41% said 600mg, and 17% said 300mg, which is a 7% increase from the last survey.

- Experience of thinking about stopping medication
  - More than 1/3 (37%) said that they have considered stopping medication. Reasons were “Side Effects”(62%) and “Economic Reasons” (40%).
  - Compared with the previous survey, patients who had considered stopping medication due to “Economic Reasons” decreased by 6%, but due to “Side Effects” increased by 7%.

- Expected success probability for clinical trial participation
  - 38% of patients said the clinical trial success probability needs to be “80% or above” as a condition to participate. 13% said they would participate if the success probability is “70% or above,” and 10% said “50% or above.” As many as 13% said they would participate under any circumstances, but 10% said they would never participate regardless the situation. While the hurdles against clinical trials are falling, patients seek a guaranteed success rate to participate.

Information sources, wanted information, requests to “Izumi”

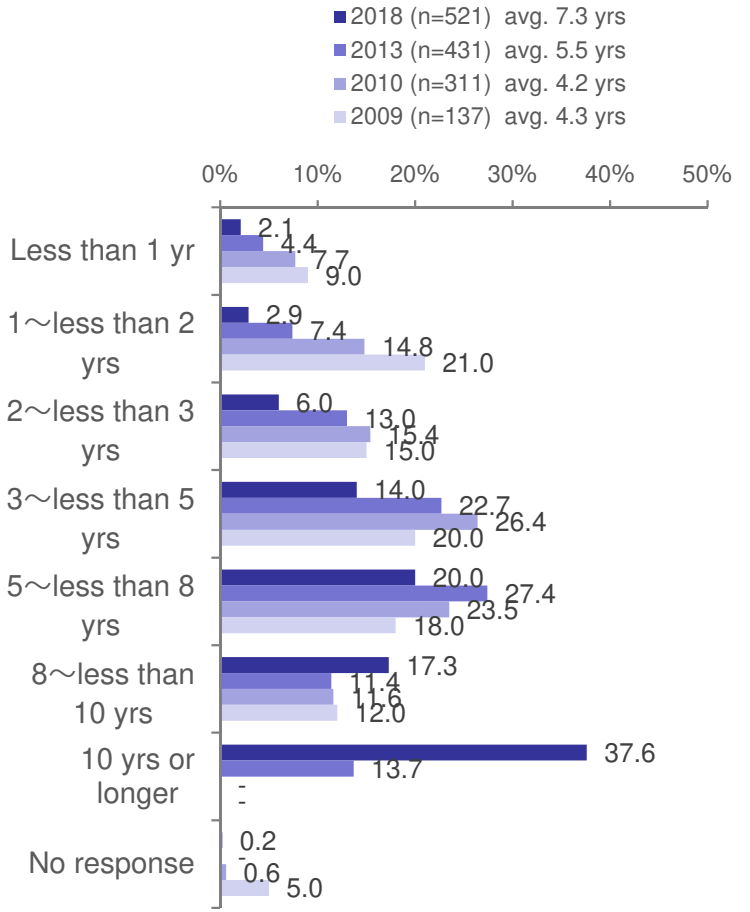
- Information sources when medical doctors are not available for consultation
  - “Patient association websites” (35%), “Pharmaceutical companies’ websites” (28%), followed by “Patient blogs” (25%), and “Booklets prepared by pharmaceutical companies” (16%). Patient associations are a very important information source for patients. Although various websites are useful information sources, both males and females over 60 do not often use them. For this age group, “Patient association gathering” is the important information source.
  - Other than medical doctors, patients consult the following professionals about diseases and treatments: “Pharmacists” (13%), “Social workers” (8%) and “Nurses” (8%), but 71% answered “Never consulted.” Those providers are not functioning as effectively as a counselor.

- Information currently wanted
  - The information patients seek most is “Future prospect” (57%), followed by “Information on new drugs” (41%), “Side effects of drugs” (37%), “New treatments”(36%), “Latest information about clinical trials” (31%), and “Personal experiences of other patients with the same conditions” (27%).
  - Compared with the previous survey, the percentage of top-ranked items, “Future prospect” and “Latest information about clinical trials,” decreased. On the contrary, information on “New drugs,” “New treatments,” “Side effects of drugs” and “Most suitable treatment method” show a slightly upward trend.
  - Even though showing a downward trend, “Future prospect” is widely wanted information. Also, interest in new possible curative methods such as “New drugs” and “New treatments” have increased. “Emotional care,” “Social rehabilitation,” and “Second opinion,” were not mentioned as frequently just like in the last survey.

- Desired improvements and requests to “Izumi”
  - Top request is “lobbying the government for lower medical cost” (48%), followed by “providing information on treatments and new drugs” (40%), “periodic patient gatherings”(27%), “offer a place where patients can easily exchange information” (24%), “regular newsletter” (24%), and “seminars and forums in various regions” (21%).

Patients' history with CML

- More than 1/3 of the respondents said "Over 10 years" since receiving CML diagnosis (38%). 20% said "Less than 5-8 years," and 17% said "Less than 8-10 years." In the previous survey (2013), the main segment was "Less than 5-8 years" (27%), followed by "3-less than 5 years" (23%). The new survey shows a longer CML history as members become older. "Over 8 years" was 55%, which is 30 points higher than the previous survey result. The average has increased by 1.8 years to 7.3 years.
- For both male and female groups, "10 years or longer" is the most common, followed by "5-less than 8 years," and "8-less than 10 years." This trend is the same in both gender groups. Average history with CML is 7.2 years for the male group and 7.5 years for the female group. Nearly half of the patients "over 60 " in both genders have "10 years or longer" history of CML.

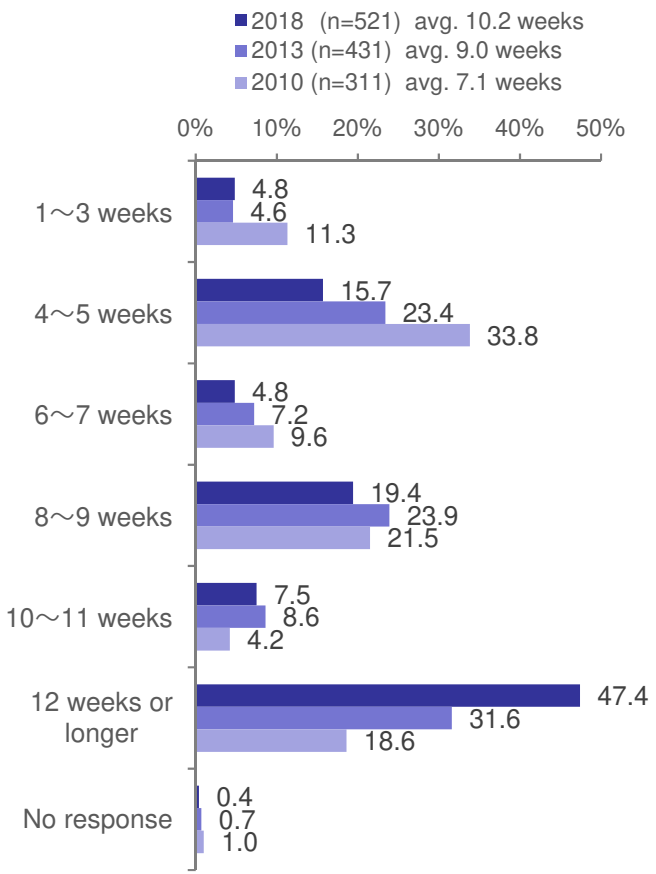


	Grand total	Make total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
	2.1	1.4	9.7	2.8	-	-	2.9	7.4	2.9	3.2	0.9	(%)
	2.9	4.7	9.7	8.3	2.7	3.1	0.8	-	2.9	-	0.9	
	6.0	5.8	9.7	8.3	1.3	6.3	6.1	7.4	5.7	4.8	7.1	
	14.0	14.4	12.9	11.1	21.3	11.8	13.5	22.2	8.6	12.9	10.7	
	20.0	21.3	32.3	16.7	29.3	14.2	18.4	29.6	20.0	16.1	16.1	
	17.3	15.9	9.7	27.8	12.0	15.7	18.9	14.8	20.0	24.2	17.9	
	37.6	36.1	16.1	25.0	32.0	48.8	39.3	18.5	40.0	38.7	46.4	
	0.2	0.4	-	-	1.3	-	-	-	-	-	-	
Avg.	7.30	7.17	5.48	6.74	7.15	7.82	7.46	6.15	7.54	7.63	7.83	

Note: "8 years and longer " was used for the 2009 and 2010 survey

Interval between hospital visits

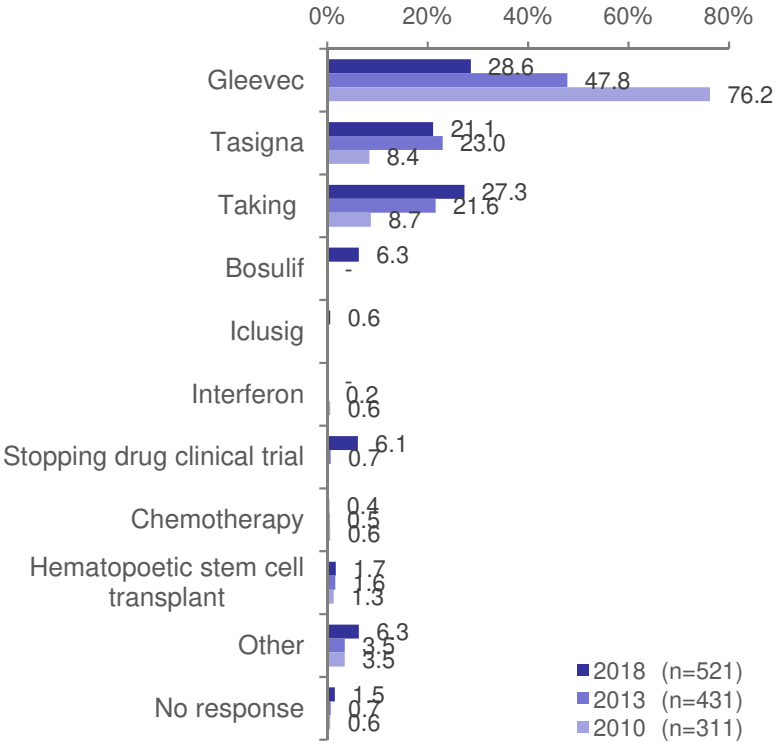
- In this survey, nearly half of the patients (47%) said the interval between hospital visits is “more than 12 weeks,” followed by “8-9 weeks” (19%), and “4-5 weeks” (16%). The average was 10.2 weeks. In the previous survey (2013), “12 weeks or more” was the most common response (32%) with an average interval being 9.0 weeks. The hospital visit interval tends to lengthen every year.
- ”12 weeks or more” is the most common answer regardless of gender. Additionally, over 50% of male patients in their 40s and 50s said “12 weeks or more,” and the vast majority of female patients in their 40s (71%) said “12 weeks or more.”



	Grand Total	Male Total	20s/30s	40s	50s	Over 60	Female Total	20s/30s	40s	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
	4.8	6.5	6.5	11.1	4.0	7.1	2.9	-	-	3.2	4.5	(%)
	15.7	13.7	19.4	11.1	10.7	13.4	18.0	37.0	14.3	9.7	16.1	
	4.8	5.4	3.2	2.8	6.7	6.3	4.1	-	-	12.9	1.8	
	19.4	19.5	16.1	13.9	22.7	19.7	19.3	22.2	8.6	16.1	24.1	
	7.5	6.9	9.7	5.6	5.3	7.1	8.2	7.4	5.7	9.7	8.9	
	47.4	48.0	45.2	55.6	50.7	46.5	46.7	29.6	71.4	48.4	43.8	
	0.4	-	-	-	-	-	0.8	3.7	-	-	0.9	

Recent treatment (1)

- Use of Gleevec has significantly decreased. The new survey indicates Gleevec use at 29% while it was 48% in 2013 and 76% in 2010. In this survey, use of Sprycel has increased from 22% to 27%. Also, a new drug, Bosulif, (6%) was added in the new survey. Patients who are participating in "Stopping medication clinical trial" increased by 6%.
- By gender and age groups, use of Gleevec is common among older patients over 60 in both male and female groups. Use of Sprycel is slightly more common among male and more females use Tasigna. The new drug, Bosulif, tends to be used more by male patients.



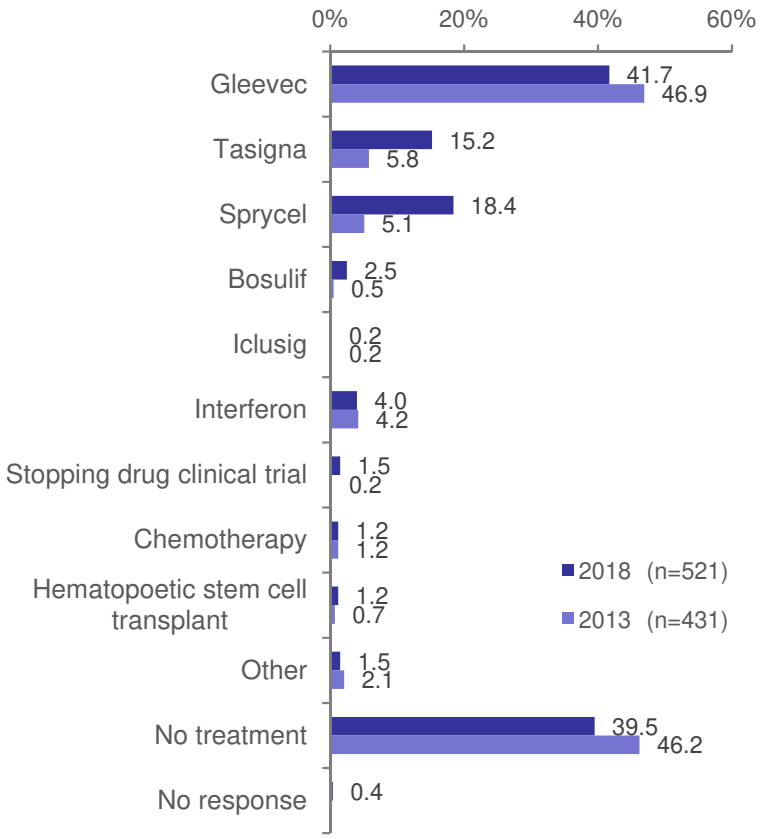
	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
	28.6	28.2	16.1	27.8	24.0	35.4	29.1	11.1	28.6	24.2	36.6	(%)
	21.1	16.6	12.9	13.9	18.7	15.0	26.2	29.6	28.6	30.6	23.2	
	27.3	29.2	51.6	33.3	32.0	21.3	25.0	29.6	31.4	24.2	21.4	
	6.3	8.3	3.2	13.9	6.7	9.4	4.1	11.1	-	4.8	2.7	
	0.6	0.4	-	-	1.3	-	0.8	3.7	-	-	0.9	
	-	-	-	-	-	-	-	-	-	-	-	
	6.1	7.2	3.2	2.8	9.3	7.9	4.9	3.7	2.9	3.2	7.1	
	0.4	0.7	-	-	1.3	0.8	-	-	-	-	-	
	1.7	2.5	6.5	-	2.7	2.4	0.8	3.7	-	-	-	
	6.3	5.8	6.5	8.3	2.7	7.1	7.0	7.4	8.6	6.5	7.1	
	1.5	1.1	-	-	1.3	0.8	2.0	-	-	6.5	0.9	

Change of medication

	Grand Total	Male					Female					Children
		Total	20s/30s	40s	50s	Over 60	Total	20s/30s	40s	50s	Over 60	Children
Base: all respondents	521	277	31	36	75	127	244	27	35	62	112	16
Stay with Gleevec	25.1	25.3	16.1	22.2	18.7	33.9	25.0	11.1	25.7	21.0	30.4	12.5
Stay with Tasigna	8.4	6.9	3.2	11.1	10.7	3.9	10.2	14.8	11.4	9.7	8.9	12.5
Stay with Sprycel	14.0	15.5	41.9	19.4	10.7	11.0	12.3	7.4	11.4	14.5	12.5	12.5
Switch from Tasigna to Gleevec	1.5	0.7	0.0	2.8	1.3	0.0	2.5	0.0	2.9	3.2	2.7	0.0
Switch from Sprycel to Gleevec	1.7	1.1	0.0	2.8	1.3	0.8	2.5	0.0	0.0	1.6	4.5	0.0
Switch from Tasigna to Sprycel	6.1	6.9	6.5	8.3	9.3	4.7	5.3	7.4	5.7	6.5	3.6	12.5
Switch from Sprycel to Tasigna	5.2	3.2	0.0	0.0	4.0	3.9	7.4	14.8	8.6	8.1	5.4	6.3
Switch from Gleevec to Tasigna	10.4	7.6	6.5	2.8	5.3	8.7	13.5	3.7	20.0	19.4	11.6	18.8
Switch from Gleevec to Sprycel	11.9	11.9	9.7	13.9	17.3	8.7	11.9	22.2	17.1	9.7	8.9	12.5
Switch from Gleevec to Bosulif	3.5	4.7	0.0	5.6	5.3	5.5	2.0	3.7	0.0	1.6	1.8	6.3
Switch from Gleevec to Iclusig	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Other	21.5	23.8	22.6	22.2	22.7	25.2	18.9	25.9	11.4	21.0	18.8	18.8

Previous treatment

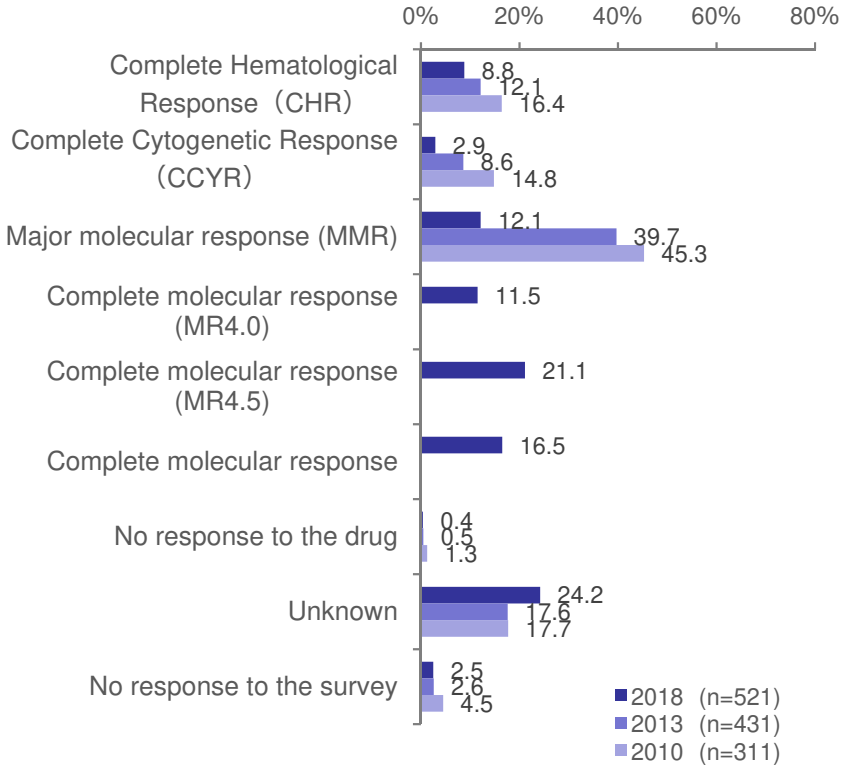
- This survey shows significant decrease in use of Gleevec and increase in use of Tasigna and Sprycel. Regarding previous treatment, 49% of current Tasigna users and 44% of current Sprycel users took Gleevec in the past.
- More female patients switch from Gleevec to Tasigna and Sprycel.



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	Recent treatment: Taking Gleevec	Recent treatment: Taking Tasigna	Recent treatment: Taking Sprycel	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	(149)	(110)	(142)	
	41.7	40.1	29.0	30.6	40.0	44.1	43.4	40.7	48.6	43.5	42.9	22.8	49.1	43.7	(%)
	15.2	14.4	22.6	19.4	14.7	11.0	16.0	25.9	20.0	17.7	11.6	5.4	5.5	22.5	
	18.4	19.5	12.9	19.4	18.7	21.3	17.2	22.2	11.4	21.0	16.1	6.0	24.5	12.0	
	2.5	2.5	-	5.6	2.7	1.6	2.5	3.7	-	1.6	3.6	0.7	3.6	3.5	
	0.2	-	-	-	-	-	0.4	-	-	-	-	-	-	-	
	4.0	2.9	-	-	2.7	4.7	5.3	11.1	5.7	3.2	5.4	4.0	7.3	0.7	
	1.5	0.7	3.2	-	-	0.8	2.5	-	2.9	3.2	2.7	0.7	0.9	1.4	
	1.2	1.4	-	2.8	-	1.6	0.8	-	-	-	1.8	2.0	0.9	0.7	
	1.2	1.1	3.2	-	-	-	1.2	-	-	4.8	-	-	-	0.7	
	1.5	1.4	-	-	2.7	1.6	1.6	-	2.9	-	2.7	2.7	0.9	0.7	
	39.5	41.5	58.1	47.2	37.3	40.2	37.3	25.9	37.1	33.9	41.1	65.1	34.5	39.4	
	0.4	0.7	-	-	1.3	0.8	-	-	-	-	-	-	-	-	

Treatment response stages

- The most common response stage is “Complete molecular response (MR4.5)” with 21%, followed by “Complete molecular response” with 17%. “Major molecular response (MMR)” accounts for 12%, “Complete molecular response (MR4.0)” is 12%, and “Complete Hematological Response (CHR)” is 9%.
- In the previous survey, the largest segment was newly introduced “Major molecular response (MMR).”Because the classification of response stages was further modified, making a comparison is difficult. Additionally, 24% said they do not know their response stage.
- The most common “Complete molecular response (MR 4.5)” is not so different between gender and age groups, but significantly higher in females in their 40s. “Complete molecular response (MR 4.0)” was higher in males, especially those in their 40s.

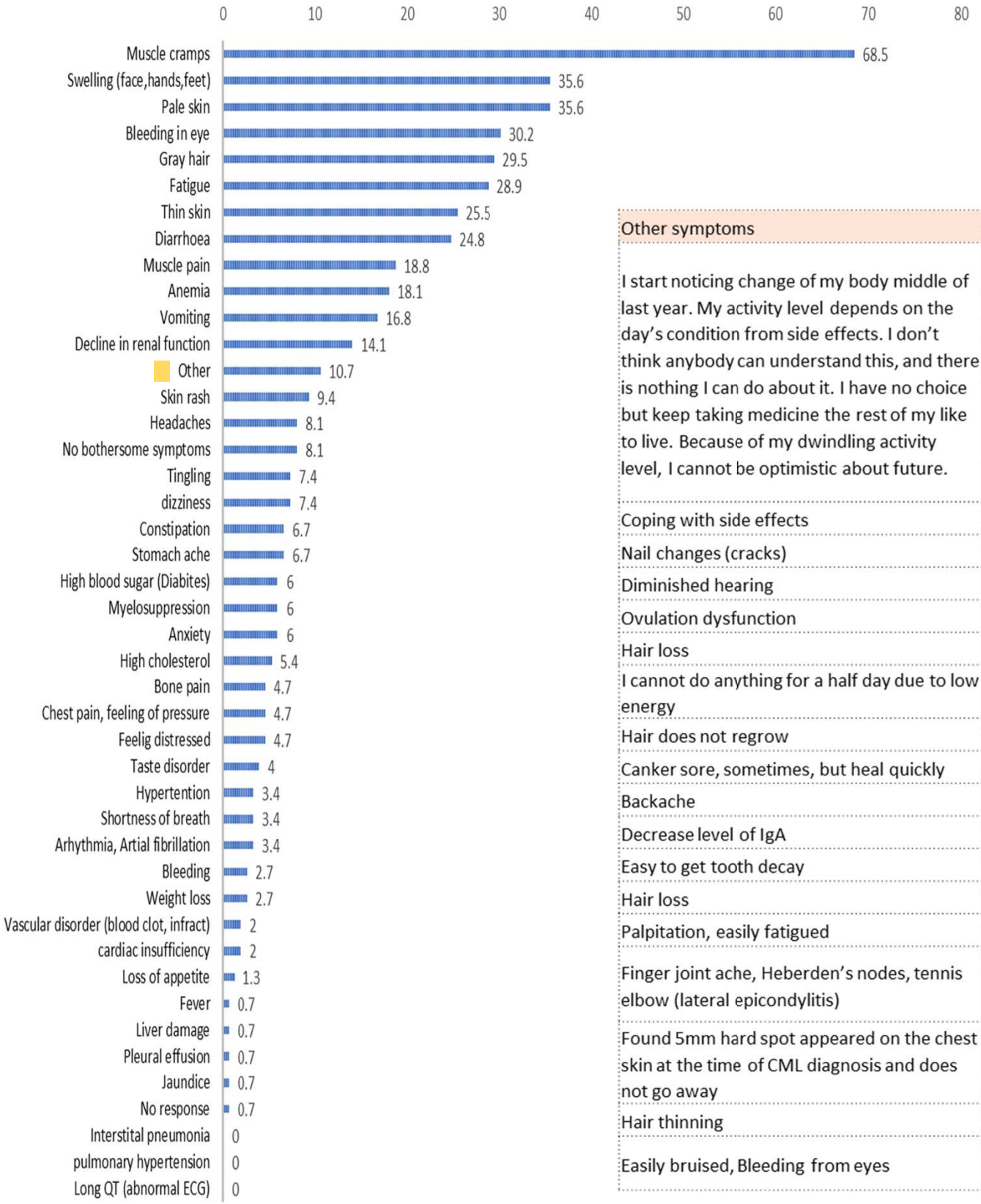


Grand total	Male total	2s/30s	40s	50s	Over 60s	Female total	20s/30s	40s	50s	Over 60s	
n (521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
8.8	9.4	6.5	2.8	8.0	13.4	8.2	14.8	5.7	6.5	8.9	(%)
2.9	2.2	3.2	2.8	2.7	1.6	3.7	7.4	2.9	-	2.7	
12.1	11.9	12.9	8.3	6.7	14.2	12.3	18.5	5.7	12.9	11.6	
11.5	14.8	19.4	30.6	17.3	8.7	7.8	11.1	8.6	4.8	8.0	
21.1	22.4	22.6	25.0	29.3	18.9	19.7	14.8	42.9	22.6	13.4	
16.5	15.5	16.1	19.4	12.0	15.7	17.6	11.1	20.0	22.6	15.2	
0.4	0.4	-	-	1.3	-	0.4	-	-	-	0.9	
24.2	21.7	19.4	11.1	21.3	24.4	27.0	14.8	11.4	29.0	35.7	
2.5	1.8	-	-	1.3	3.1	3.3	7.4	2.9	1.6	3.6	

Note: ”Major molecular response (MMR)” was used in the 2013 and 2010 survey

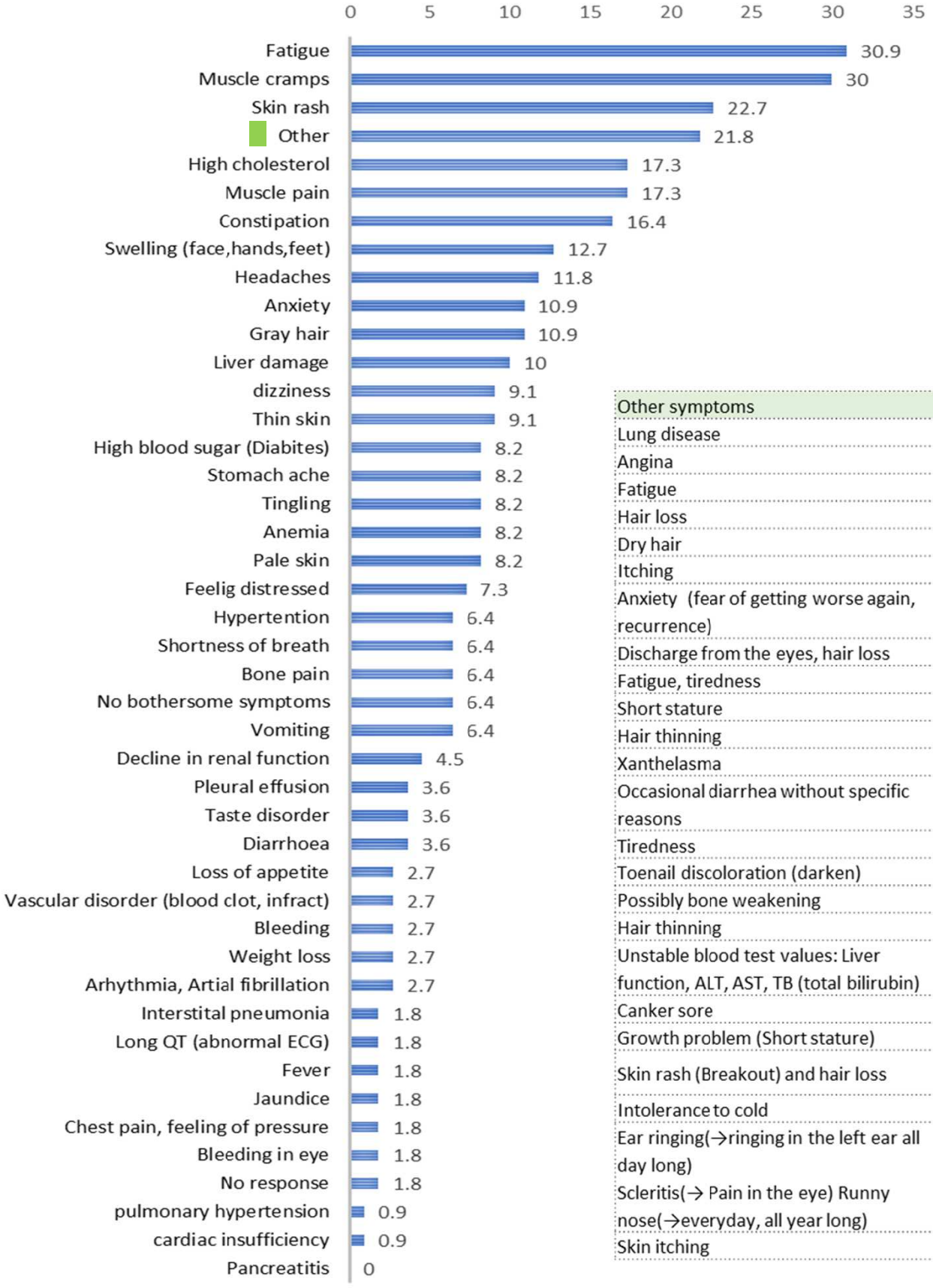
GLEEVEC SIDE EFFECTS N=149

(PERCENTAGE PER SYMPTOM)

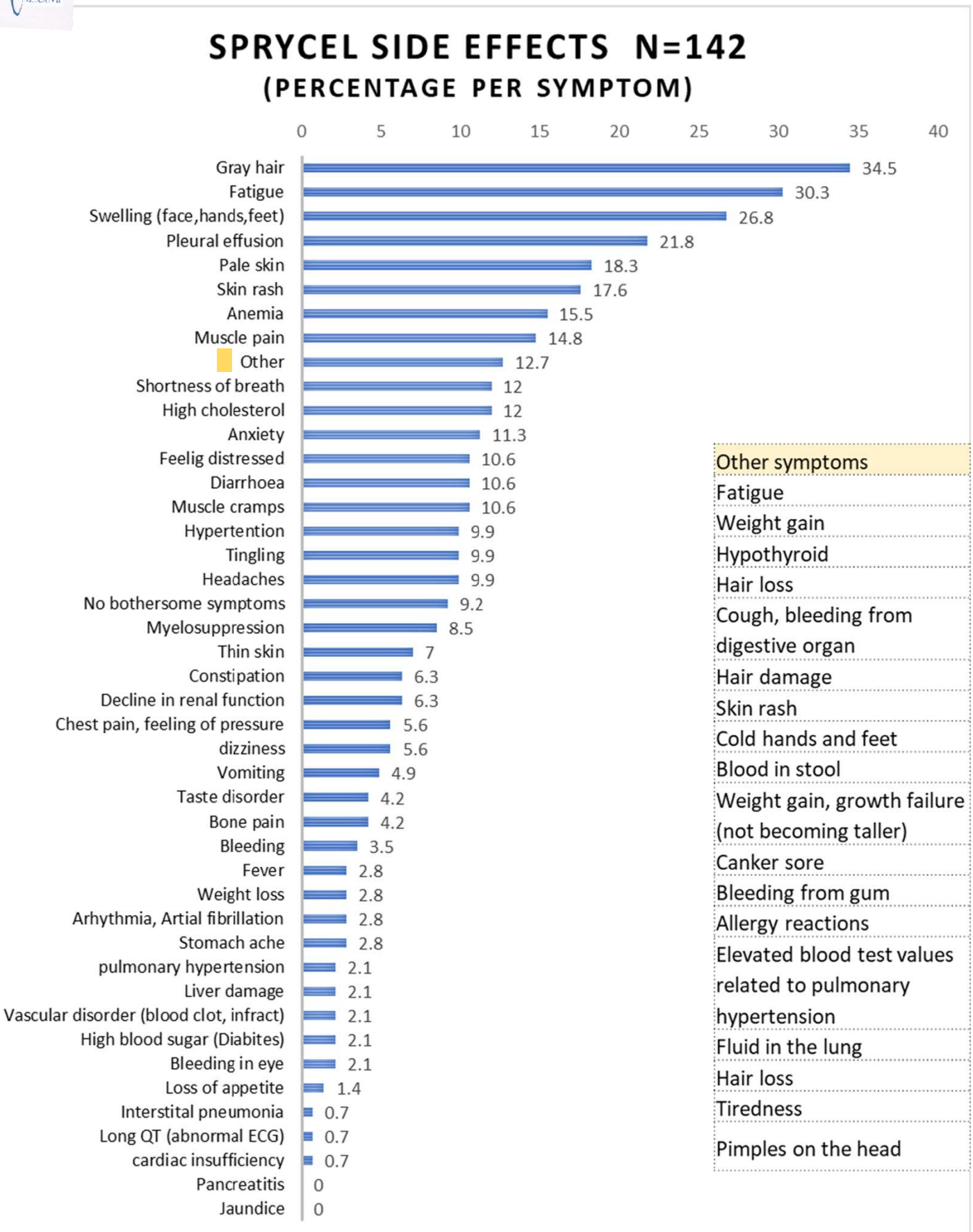


Other symptoms
I start noticing change of my body middle of last year. My activity level depends on the day's condition from side effects. I don't think anybody can understand this, and there is nothing I can do about it. I have no choice but keep taking medicine the rest of my like to live. Because of my dwindling activity level, I cannot be optimistic about future.
Coping with side effects
Nail changes (cracks)
Diminished hearing
Ovulation dysfunction
Hair loss
I cannot do anything for a half day due to low energy
Hair does not regrow
Canker sore, sometimes, but heal quickly
Backache
Decrease level of IgA
Easy to get tooth decay
Hair loss
Palpitation, easily fatigued
Finger joint ache, Heberden's nodes, tennis elbow (lateral epicondylitis)
Found 5mm hard spot appeared on the chest skin at the time of CML diagnosis and does not go away
Hair thinning
Easily bruised, Bleeding from eyes

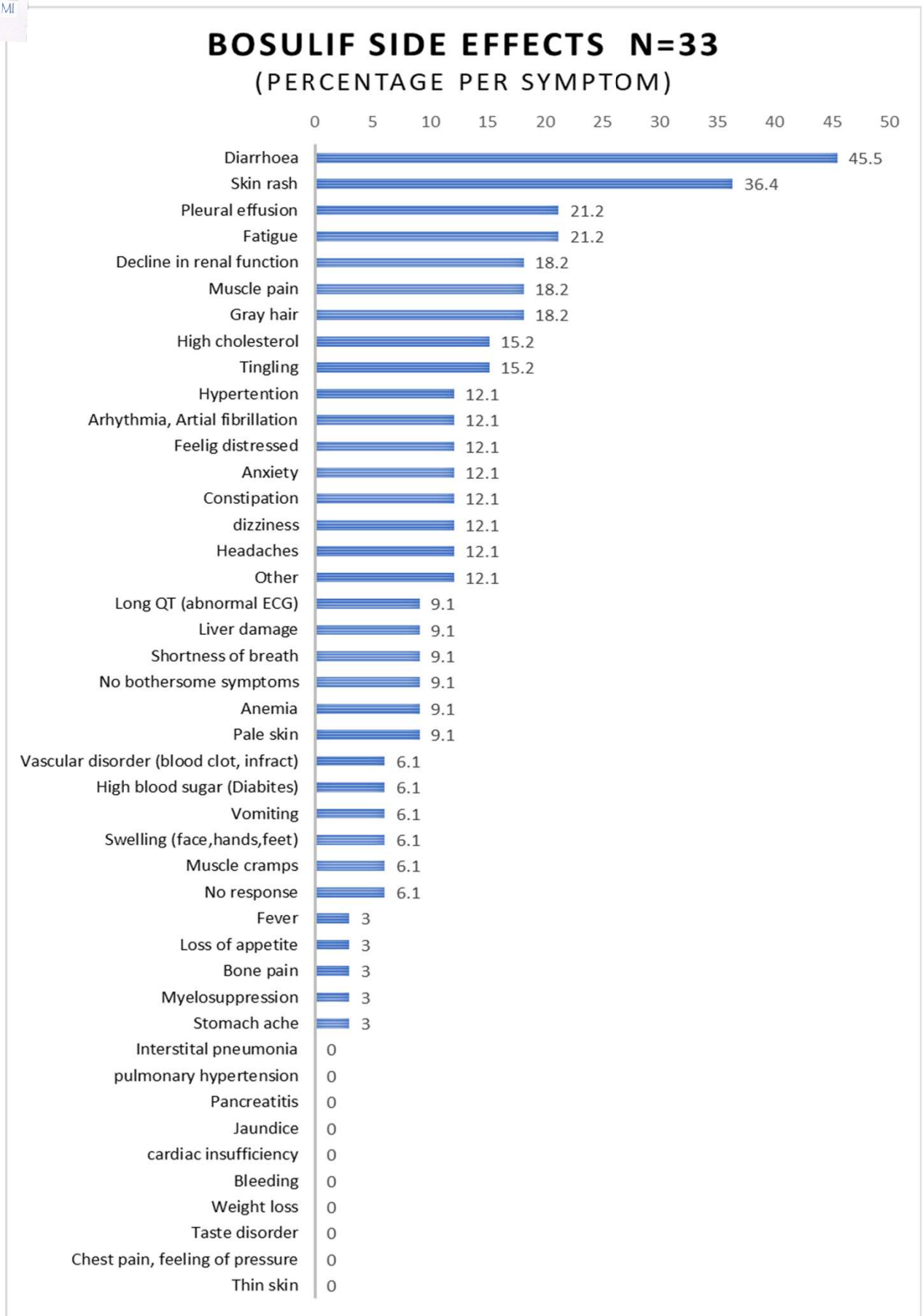
TASIGNA SIDE EFFECTS N=110
(PERCENTAGE PER SYMPTOM)



Other symptoms
Lung disease
Angina
Fatigue
Hair loss
Dry hair
Itching
Anxiety (fear of getting worse again, recurrence)
Discharge from the eyes, hair loss
Fatigue, tiredness
Short stature
Hair thinning
Xanthelasma
Occasional diarrhea without specific reasons
Tiredness
Toenail discoloration (darken)
Possibly bone weakening
Hair thinning
Unstable blood test values: Liver function, ALT, AST, TB (total bilirubin)
Canker sore
Growth problem (Short stature)
Skin rash (Breakout) and hair loss
Intolerance to cold
Ear ringing(→ringing in the left ear all day long)
Scleritis(→ Pain in the eye) Runny nose(→everyday, all year long)
Skin itching

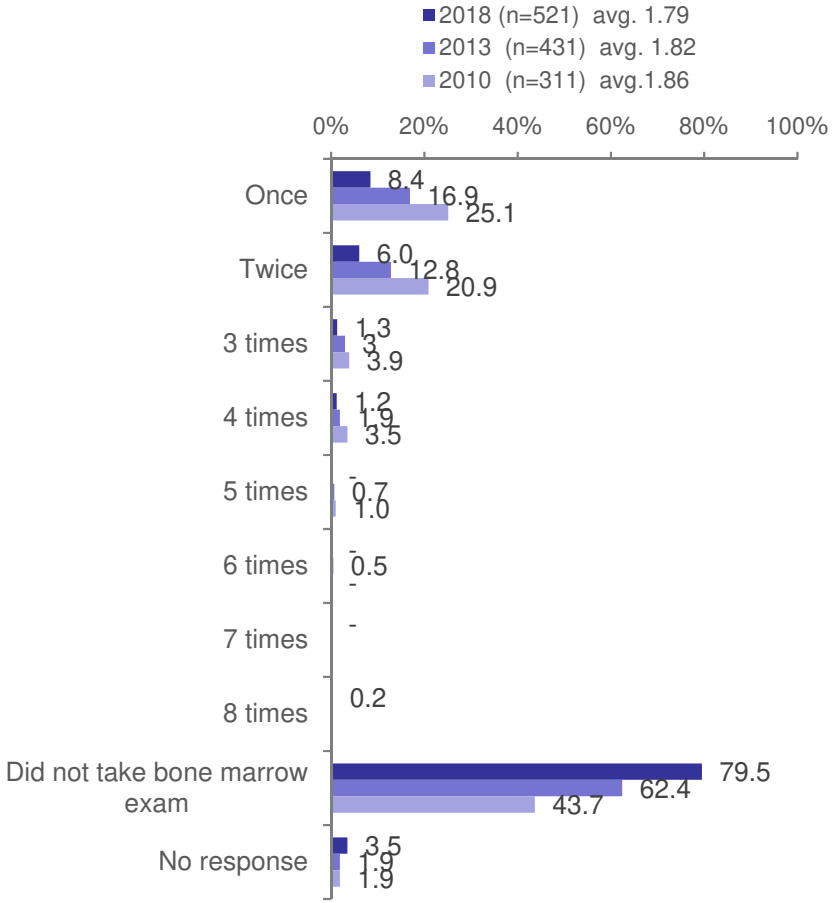


Other symptoms
Fatigue
Weight gain
Hypothyroid
Hair loss
Cough, bleeding from digestive organ
Hair damage
Skin rash
Cold hands and feet
Blood in stool
Weight gain, growth failure (not becoming taller)
Canker sore
Bleeding from gum
Allergy reactions
Elevated blood test values related to pulmonary hypertension
Fluid in the lung
Hair loss
Tiredness
Pimples on the head


BOSULIF SIDE EFFECTS N=33
(PERCENTAGE PER SYMPTOM)
0 5 10 15 20 25 30 35 40 45 50
Diarrhoea 45.5
Skin rash 36.4
Pleural effusion 21.2
Fatigue 21.2
Decline in renal function 18.2
Muscle pain 18.2
Gray hair 18.2
High cholesterol 15.2
Tingling 15.2
Hypertention 12.1
Arhythmia, Artial fibrillation 12.1
Feelig distressed 12.1
Anxiety 12.1
Constipation 12.1
dizziness 12.1
Headaches 12.1
Other 12.1
Long QT (abnormal ECG) 9.1
Liver damage 9.1
Shortness of breath 9.1
No bothersome symptoms 9.1
Anemia 9.1
Pale skin 9.1
Vascular disorder (blood clot, infract) 6.1
High blood sugar (Diabites) 6.1
Vomiting 6.1
Swelling (face,hands,feet) 6.1
Muscle cramps 6.1
No response 6.1
Fever 3
Loss of appetite 3
Bone pain 3
Myelosuppression 3
Stomach ache 3
Interstital pneumonia 0
pulmonary hypertension 0
Pancreatitis 0
Jaundice 0
cardiac insufficiency 0
Bleeding 0
Weight loss 0
Taste disorder 0
Chest pain, feeling of pressure 0
Thin skin 0

Number of bone marrow tests in the past year

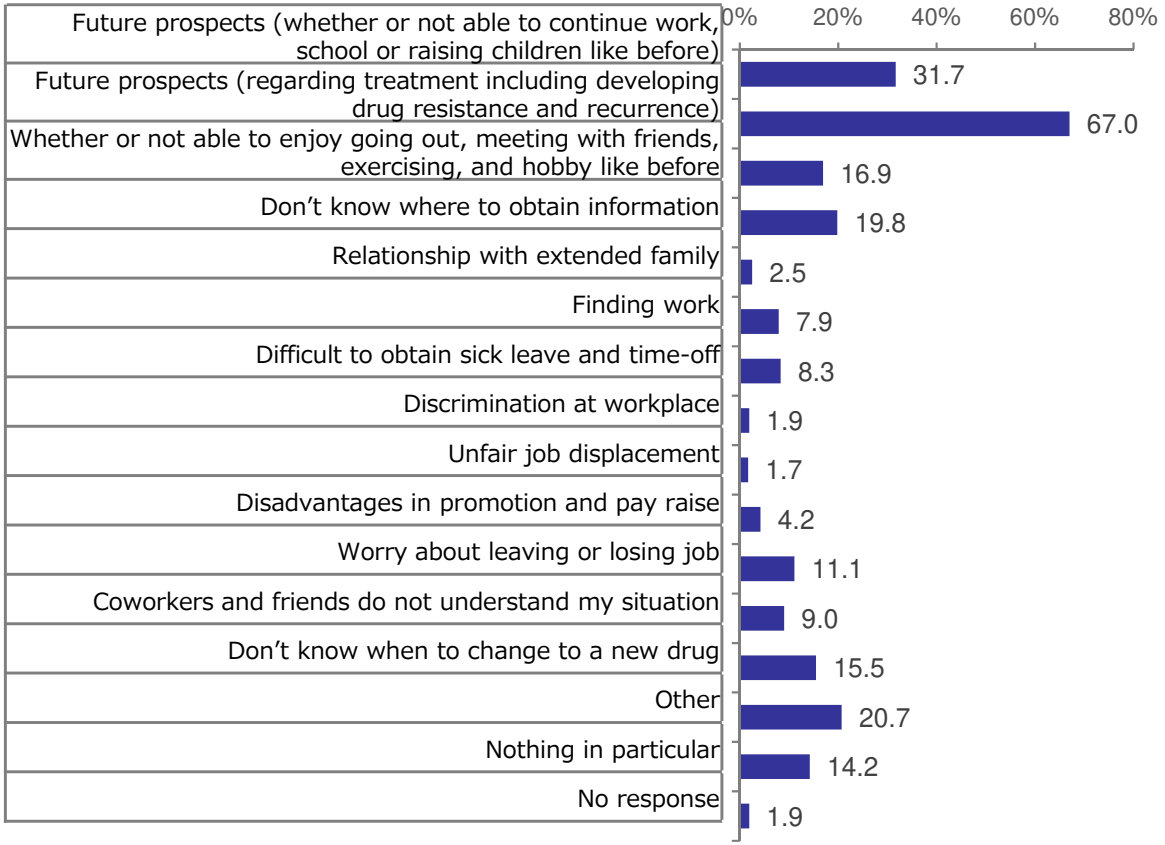
- Eight-tenths of the respondents (80%) have not had a bone marrow test in the past year. Compared with the previous two surveys, fewer people are taking a bone marrow test. Among those who had a bone marrow test, the frequency was "Once" 6%; "Twice" 6%; and "3 times or more" 4%. Overall average frequency per year was 0.3 times, which is half of the last survey. Many patients avoid the test due to pain (satisfaction rate 4.95). Among those who took the test, frequency was approximately twice (1.79 times) per year.
- By gender, more females (82%) did not take the bone marrow test compared with males (78%). In the last survey, more females (65%) did not take the test compared with males (60%). In an age group comparison, more middle and older generations (40s, 50s, 60 and above) said "Did not take the test" than 20s/30s in both genders.



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
	8.4	9.0	19.4	5.6	9.3	6.3	7.8	18.5	8.6	6.5	6.3	(%)
	6.0	7.2	6.5	11.1	10.7	4.7	4.5	7.4	2.9	6.5	3.6	
	1.3	1.1	3.2	-	1.3	-	1.6	3.7	2.9	-	0.9	
	1.2	0.4	-	-	-	0.8	2.0	3.7	5.7	1.6	0.9	
	-	-	-	-	-	-	-	-	-	-	-	
	-	-	-	-	-	-	-	-	-	-	-	
	-	-	-	-	-	-	-	-	-	-	-	
	0.2	0.4	-	-	-	0.8	-	-	-	-	-	
	79.5	77.6	64.5	80.6	77.3	81.1	81.6	66.7	77.1	85.5	83.9	
	3.5	4.3	6.5	2.8	1.3	6.3	2.5	-	2.9	-	4.5	
Avg.	1.79	1.72	1.44	1.67	1.63	2.00	1.87	1.78	2.29	1.78	1.69	

Difficulties during treatment

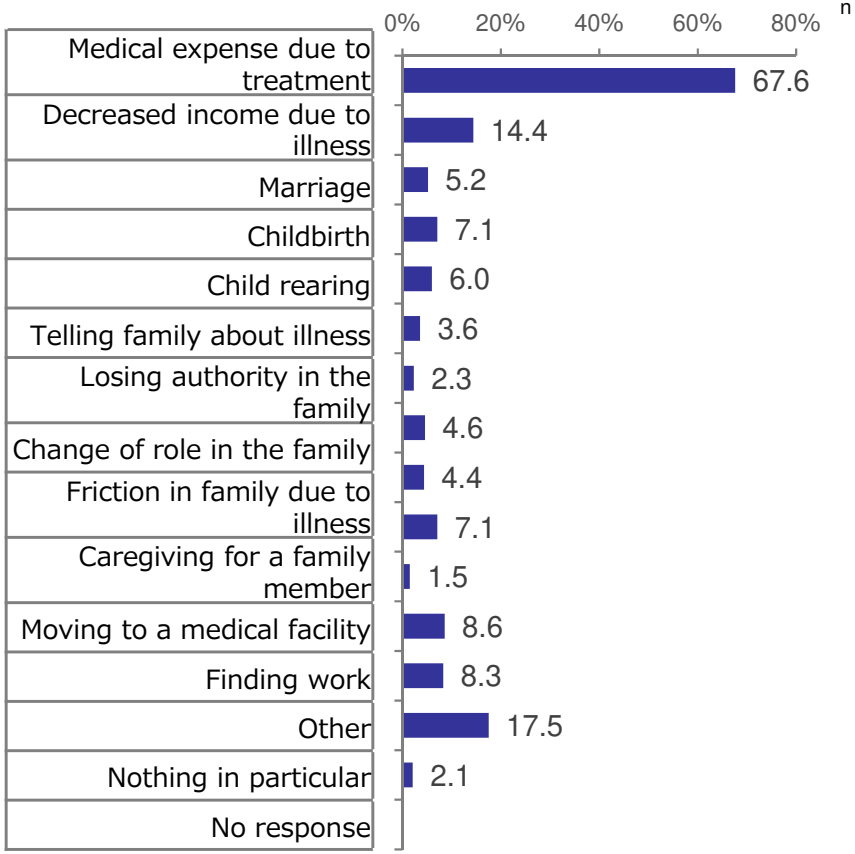
- By gender, slightly more males than females mentioned “Future prospects (whether or not able to continue work, study, and child rearing).” Female patients mentioned more “Future prospects regarding treatment (developing drug resistance and recurrence),” but the difference is minimal between genders.
- By age groups, many younger generation males in their 20s/30s, and 40s and females in their 20s/30s worry about future prospects. Also males in their 20s/30s and 40s and females in their 60s or above said “Don’t know where to obtain information.” Males in their 20s/30s and females in 20s/30s and 40s see difficulties in “Finding work.” Males in their 20s/30s and 40s, and females in their 40s worry about “Losing job.” Both genders in their 20s/30s find it difficult to take “Paid sick leave and unpaid time off.” Younger generations in both genders suffer from significant anxiety and uneasiness.



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
Future prospects (whether or not able to continue work, school or raising children like before)	31.7	33.9	58.1	55.6	44.0	14.2	29.1	51.9	37.1	35.5	14.3	(%)
Future prospects (regarding treatment including developing drug resistance and recurrence)	67.0	65.3	80.6	86.1	72.0	52.0	68.9	81.5	65.7	67.7	67.0	
Whether or not able to enjoy going out, meeting with friends, exercising, and hobby like before	16.9	16.6	16.1	27.8	18.7	12.6	17.2	22.2	8.6	17.7	18.8	
Don’t know where to obtain information	19.8	18.8	29.0	25.0	14.7	16.5	20.9	3.7	14.3	21.0	26.8	
Relationship with extended family	2.5	2.5	9.7	8.3	1.3	-	2.5	3.7	5.7	-	2.7	
Finding work	7.9	7.6	25.8	8.3	6.7	0.8	8.2	18.5	20.0	8.1	0.9	
Difficult to obtain sick leave and time-off	8.3	8.7	19.4	16.7	12.0	1.6	7.8	22.2	11.4	12.9	-	
Discrimination at workplace	1.9	2.2	3.2	11.1	-	-	1.6	3.7	2.9	1.6	0.9	
Unfair job displacement	1.7	2.5	6.5	11.1	-	-	0.8	-	2.9	1.6	-	
Disadvantages in promotion and pay raise	4.2	5.4	12.9	13.9	5.3	0.8	2.9	7.4	2.9	6.5	-	
Worry about leaving or losing job	11.1	12.6	22.6	22.2	18.7	3.1	9.4	14.8	20.0	17.7	-	
Coworkers and friends do not understand my situation	9.0	9.0	19.4	19.4	10.7	1.6	9.0	22.2	5.7	9.7	4.5	
Don’t know when to change to a new drug	15.5	14.8	9.7	25.0	18.7	11.8	16.4	7.4	17.1	21.0	14.3	
Other	20.7	20.6	25.8	8.3	25.3	18.9	20.9	33.3	17.1	27.4	14.3	
Nothing in particular	14.2	16.2	6.5	11.1	10.7	23.6	11.9	3.7	5.7	8.1	18.8	
No response	1.9	1.8	3.2	-	-	3.1	2.0	3.7	-	1.6	2.7	

Difficulties in family life

- No significant difference between genders
- By age groups, many males in their 40s and 50s, and females in their 20s/30s and 50s mention “Medical expense.”
  More people in their 20s/30s in both genders show concerns about “Marriage” and “Childbirth.”
  Many male patients in their 20s/30s and females in their 40s worry about “Finding work.” Also many males in their 40s mentioned “Child rearing” and “Friction in family due to illness.”

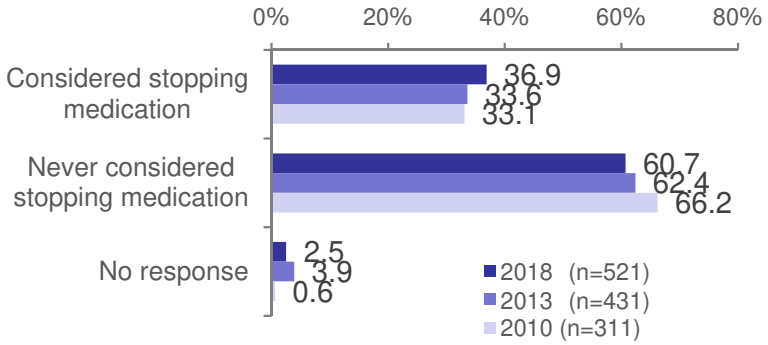


	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	5s	Over 60	
	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
Medical expense due to treatment	67.6	68.2	64.5	80.6	77.3	62.2	66.8	77.8	74.3	82.3	56.3	(%)
Decreased income due to illness	14.4	15.5	19.4	19.4	18.7	11.8	13.1	14.8	14.3	21.0	8.9	
Marriage	5.2	5.1	32.3	5.6	-	0.8	5.3	40.7	2.9	-	-	
Childbirth	7.1	5.1	29.0	8.3	-	0.8	9.4	63.0	11.4	-	-	
Child rearing	6.0	7.6	12.9	22.2	8.0	1.6	4.1	11.1	11.4	4.8	-	
Telling family about illness	3.6	4.0	9.7	8.3	5.3	0.8	3.3	3.7	8.6	4.8	0.9	
Losing authority in the family	2.3	3.6	-	8.3	4.0	3.1	0.8	-	-	1.6	0.9	
Change of role in the family	4.6	4.0	6.5	5.6	2.7	3.1	5.3	-	8.6	4.8	6.3	
Friction in family due to illness	4.4	5.4	6.5	16.7	4.0	1.6	3.3	3.7	-	4.8	3.6	
Caregiving for a family member	7.1	5.4	3.2	5.6	5.3	5.5	9.0	-	2.9	6.5	15.2	
Moving to a medical facility	1.5	0.7	-	-	1.3	0.8	2.5	-	2.9	-	4.5	
Finding work	8.6	9.0	32.3	11.1	10.7	0.8	8.2	14.8	25.7	8.1	0.9	
Other	8.3	6.9	-	2.8	8.0	8.7	9.8	-	11.4	4.8	14.3	
Nothing in particular	17.5	19.1	6.5	13.9	17.3	22.8	15.6	3.7	11.4	12.9	19.6	
No response	2.1	1.4	-	-	-	3.1	2.9	-	2.9	-	5.4	

Experience of considering stopping taking medication and reasons

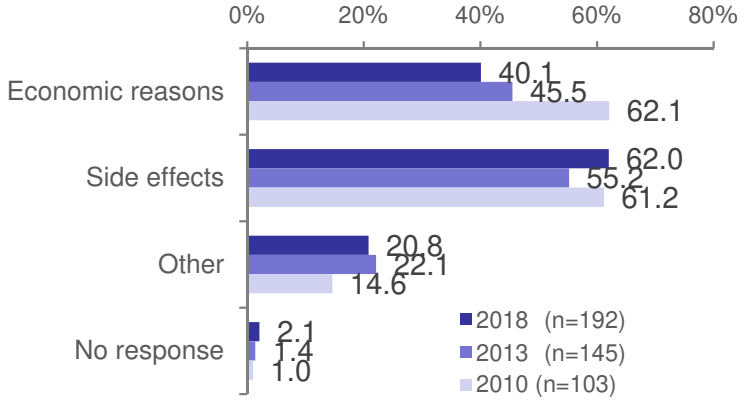
- 37% of the total respondents answered that they have “Considered stopping medications.”
- By gender and age group, more females had “Considered stopping taking medicine,” and 59% of females in their 20s/30s thought about stopping.
- Common reasons to consider stopping medications are “Economic reasons” (40%) and “Side effects” (62%) in this survey. In the previous survey, “Side effects” (55%) was the leading cause while “Economic reasons” accounted for 46%. Economic reasons are declining year by year, but financial problems still remain when it comes to stopping medication.

Experience of considering stopping taking medicine



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
Considered stopping medication	36.9	34.7	35.5	38.9	33.3	35.4	39.3	59.3	40.0	40.3	35.7	(%)
Never considered stopping medication	60.7	63.2	61.3	61.1	65.3	61.4	57.8	40.7	60.0	56.5	59.8	
No response	2.5	2.2	3.2	-	1.3	3.1	2.9	-	-	3.2	4.5	

Reason to consider stopping



(192)	(96)	(11)	(14)	(25)	(45)	(96)	(16)	(14)	(25)	(40)	
40.1	40.6	45.5	64.3	36.0	35.6	39.6	37.5	42.9	56.0	30.0	
62.0	63.5	45.5	57.1	76.0	62.2	60.4	62.5	42.9	56.0	70.0	
20.8	15.6	18.2	-	16.0	20.0	26.0	25.0	50.0	24.0	17.5	
2.1	2.1	-	-	4.0	2.2	2.1	-	7.1	-	2.5	

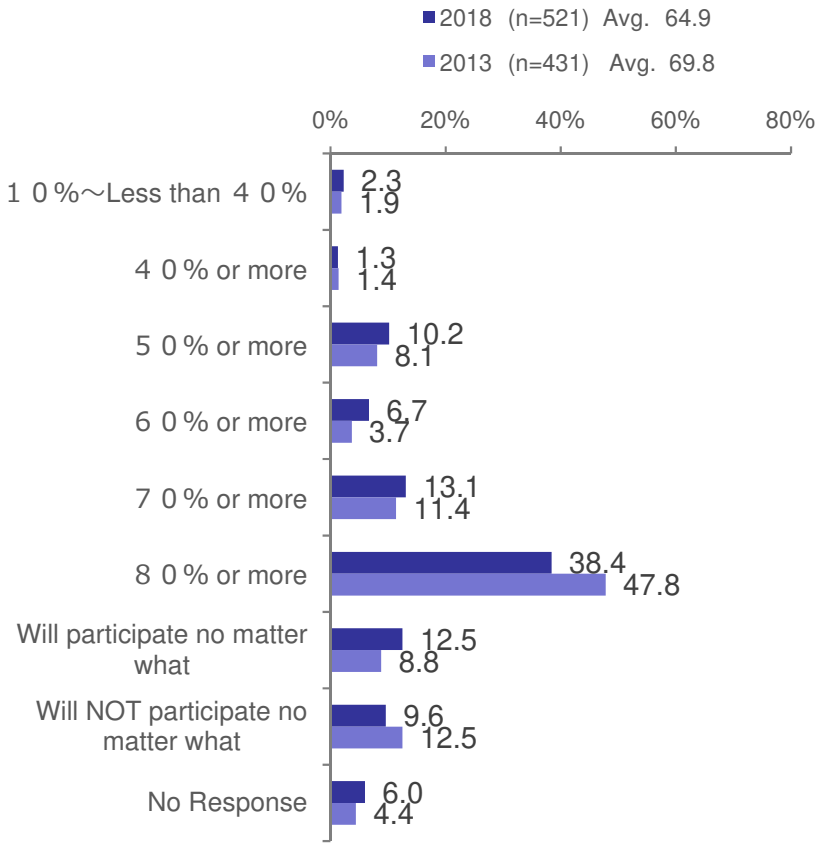
Q20. Experience of thinking about stopping medication and reasons

	TOTAL	CML medication change status									
		Continue Gleevec	Continue Tasigna	Continue Sprycel	Change from Tasigna to Gleevec	Change from Sprycel to Gleevec	Change from Tasigna to Sprycel	Change from Sprycel to Tasigna	Change from Gleevec to Tasigna	Change from Gleevec to Sprycel	Change from Gleevec to Bosulif
Base: All respondents	521	131	44	73	8	9	32	27	54	62	18
1. Have considered stopping	36.9	32.8	40.9	23.3	25	44.4	40.6	48.1	33.3	38.7	22.2
2. Never considered stopping	60.7	64.9	59.1	76.7	75	55.6	59.4	51.9	66.7	61.3	77.8
No response	2.5	2.3	0	0	0	0	0	0	0	0	0

	TOTAL	CML medication change status									
		Continue Gleevec	Continue Tasigna	Continue Sprycel	Change from Tasigna to Gleevec	Change from Sprycel to Gleevec	Change from Tasigna to Sprycel	Change from Sprycel to Tasigna	Change from Gleevec to Tasigna	Change from Gleevec to Sprycel	Change from Gleevec to Bosulif
Base: Respondents considered stopping	192	43	18	17	2	4	13	13	18	24	4
1. Economic reasons	40.1	32.6	44.4	41.2	50	25	30.8	61.5	44.4	58.3	50
2. Side effects	62	60.5	61.1	70.6	100	100	76.9	61.5	72.2	58.3	75
3. Other	20.8	25.6	11.1	5.9	0	0	7.7	23.1	33.3	12.5	0
No response	2.1	2.3	5.6	0	0	0	0	0	0	4.2	0

Success Probability for Clinical Trial Participation

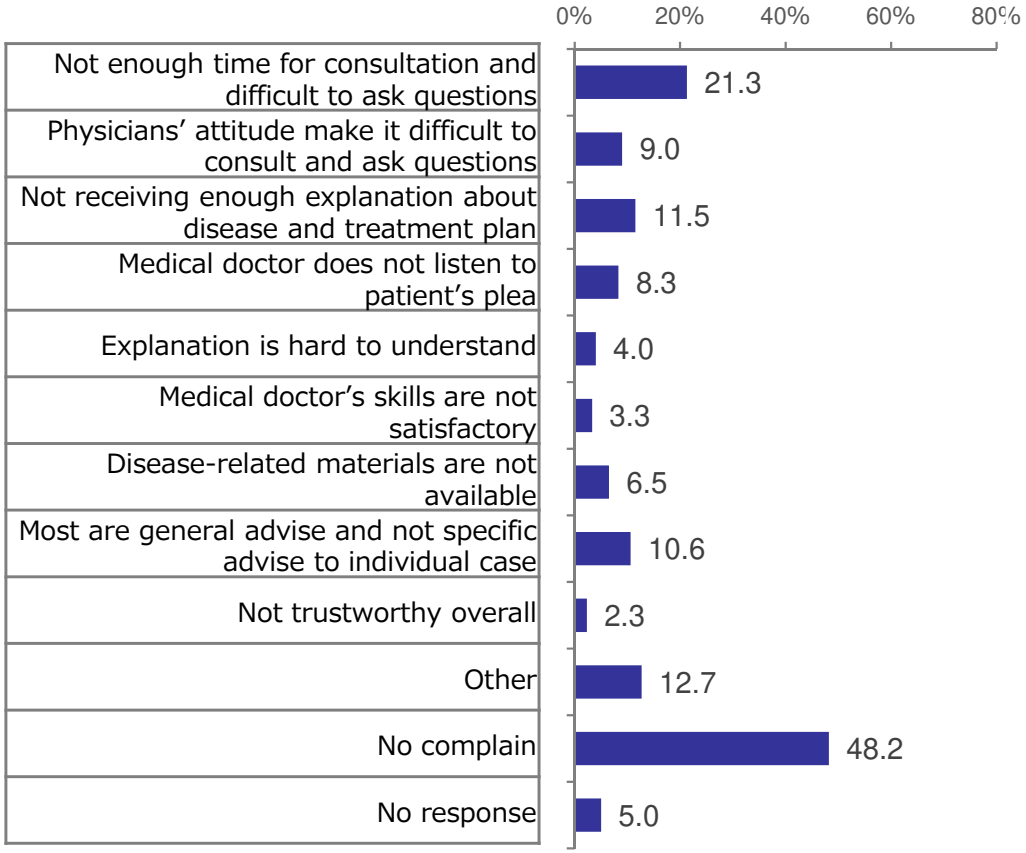
- 38% of respondents said they would participate in the stopping medication clinical trial if the success probability is “80% or more.” 13% said they would participate if the probability of success is “70% or more,” and 10% said “50% or more.” While the other 13% said they would participate under any circumstances, 10% said “Never participate regardless the situation.” In the previous survey, 48% chose “80% or more” success probability, 23% chose “50-70% or more success” (In the new survey, 30% choose “50-70% or more success” for them to participate in the clinical trial). Hurdles against clinical trial are falling.
- By gender and age groups, 34% of male and 43% of female patients want “80% or higher.” Males are more willing to participate with lower success rates than females. However, more than half (52%) of the females in their 20s/30s are willing to participate with a relatively lower success rate (50%-70% or more).
- By recent treatment groups, compared with Gleevec users, Tasigna and Sprycel users accept a lower probability of success.



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60	Recent Treatment: Taking Gleevec	Recent Treatment: Taking Tasigna	Recent Treatment: Taking Sprycel	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	(149)	(110)	(142)	
	2.3	3.2	6.5	2.8	-	4.7	1.2	-	-	1.6	1.8	3.4	3.6	0.7	(%)
	1.3	1.4	-	2.8	2.7	0.8	1.2	-	2.9	1.6	0.9	2.0	0.9	1.4	
	10.2	11.6	6.5	11.1	8.0	15.7	8.6	14.8	-	12.9	5.4	6.0	5.5	12.0	
	6.7	7.6	3.2	13.9	10.7	5.5	5.7	3.7	5.7	4.8	7.1	5.4	5.5	7.7	
	13.1	12.6	12.9	13.9	12.0	12.6	13.5	33.3	5.7	17.7	9.8	7.4	12.7	15.5	
	38.4	33.9	45.2	38.9	32.0	29.1	43.4	33.3	68.6	38.7	39.3	49.0	36.4	42.3	
	12.5	13.4	16.1	13.9	16.0	11.8	11.5	14.8	5.7	11.3	13.4	10.7	18.2	12.0	
	9.6	9.0	3.2	-	12.0	11.0	10.2	-	11.4	6.5	15.2	13.4	14.5	4.9	
	6.0	7.2	6.5	2.8	6.7	8.7	4.5	-	-	4.8	7.1	2.7	2.7	3.5	
Avg.	64.90	62.56	63.04	63.71	61.89	61.23	67.50	65.37	76.94	66.18	65.06	67.72	60.60	66.81	

Discontent about medical doctors

- Slightly more female patients than males said “Not enough time for consultation and questions,” but there is no gender difference in other dissatisfaction points. Viewed by age groups, discontent on “Not enough time for consultation” is the most common among females in their 20s/30s and 40s. Males in their 40s and females in their 50s show strong discontent about “Not receiving enough explanation about the disease and treatment plan.” Additionally, 26% of males in their 20s/30s are frustrated by “Too much general information but not enough specific advice for individual case.” However, only 10% in same age group complains about “Not enough time for consultation,” which is the most common dissatisfaction overall.
- Half of male patients said they do not feel particularly dissatisfied, but slightly fewer females (46%) than males feel that way.

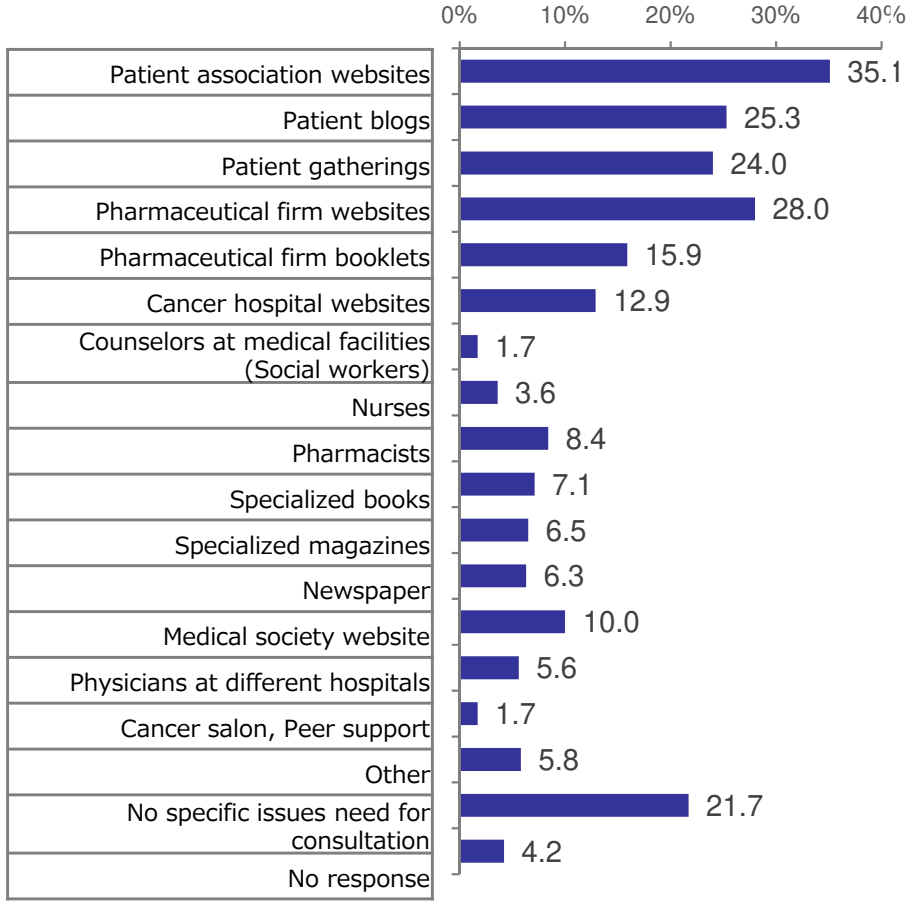


	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40s	50s	Over 60
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)
	21.3	19.9	9.7	13.9	24.0	22.8	23.0	29.6	25.7	21.0	23.2
	9.0	9.4	6.5	8.3	12.0	9.4	8.6	3.7	17.1	8.1	8.0
	11.5	11.2	9.7	22.2	10.7	9.4	11.9	-	-	21.0	13.4
	8.3	8.7	3.2	8.3	12.0	8.7	7.8	14.8	5.7	4.8	8.9
	4.0	4.7	3.2	11.1	1.3	5.5	3.3	3.7	-	3.2	4.5
	3.3	2.9	3.2	2.8	2.7	3.1	3.7	7.4	-	3.2	4.5
	6.5	6.1	6.5	5.6	5.3	7.1	7.0	-	2.9	8.1	8.9
	10.6	10.1	25.8	13.9	8.0	7.1	11.1	3.7	17.1	9.7	11.6
	2.3	2.2	6.5	2.8	-	2.4	2.5	-	-	3.2	3.6
	12.7	10.8	6.5	22.2	12.0	8.7	14.8	14.8	14.3	16.1	11.6
	48.2	50.2	48.4	38.9	50.7	51.2	45.9	40.7	51.4	43.5	46.4
	5.0	4.7	9.7	-	4.0	4.7	5.3	7.4	2.9	6.5	5.4

(%)

Information sources other than medical doctors

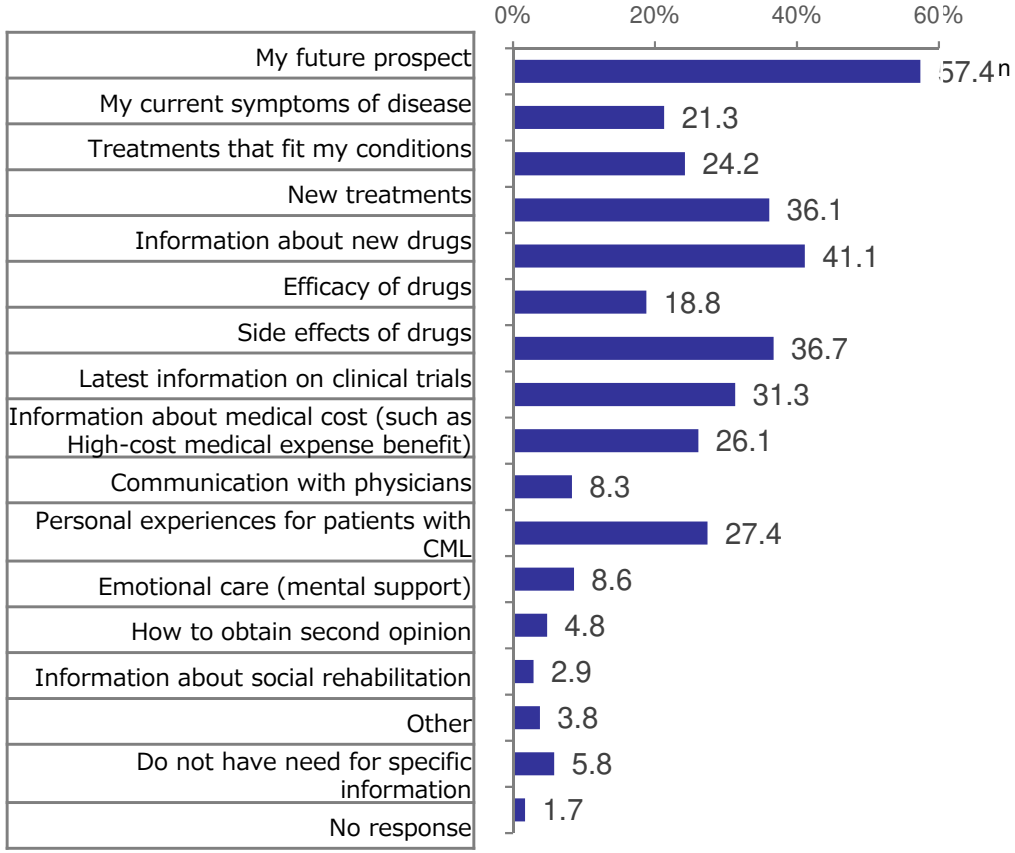
- By gender and age groups, more male patients use “Pharmaceutical company websites,” “Cancer hospital websites” and “Medical society websites” as information sources. Especially males in their 50s mentioned “Pharmaceutical company websites” and “Cancer hospital websites” more while many males in their 20s/30s and 40s use “Medical society websites.”
- In contrast, female patients use “Patient blogs” and “Pharmaceutical company booklets” for information. Females in their 20s/30s and 40s mentioned “patient blogs” most.
- Although “Patient association websites,” “Pharmaceutical company websites” and “Patient blogs” are the most common information sources, they are not generally used by older patients in their 60s in both genders. Use of “Patient association gathering” is significantly low among males in their 20s/30s, and 60s and above in both genders.



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40a	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
Patient association websites	35.1	33.9	29.0	44.4	46.7	26.0	36.5	51.9	42.9	50.0	23.2	(%)
Patient blogs	25.3	23.5	19.4	41.7	30.7	15.0	27.5	48.1	42.9	29.0	14.3	
Patient gatherings	24.0	23.1	12.9	36.1	25.3	18.9	25.0	22.2	20.0	37.1	17.0	
Pharmaceutical firm websites	28.0	30.3	32.3	30.6	40.0	24.4	25.4	37.0	31.4	25.8	17.9	
Pharmaceutical firm booklets	15.9	14.1	16.1	19.4	13.3	12.6	18.0	14.8	20.0	14.5	20.5	
Cancer hospital websites	12.9	14.8	16.1	8.3	24.0	11.0	10.7	11.1	17.1	12.9	8.0	
Counselors at medical facilities (Social workers)	1.7	1.8	-	2.8	2.7	1.6	1.6	-	-	1.6	2.7	
Nurses	3.6	3.2	3.2	2.8	2.7	3.9	4.1	-	2.9	3.2	5.4	
Pharmacists	8.4	7.2	3.2	11.1	2.7	10.2	9.8	3.7	-	9.7	15.2	
Specialized books	7.1	9.0	9.7	11.1	9.3	7.9	4.9	-	11.4	1.6	5.4	
Specialized magazines	6.5	8.3	6.5	5.6	9.3	9.4	4.5	3.7	8.6	-	5.4	
Newspaper	6.3	7.2	6.5	2.8	4.0	11.0	5.3	-	5.7	1.6	8.0	
Medical society website	10.0	14.1	19.4	19.4	12.0	12.6	5.3	7.4	8.6	1.6	5.4	
Physicians at different hospitals	5.6	4.0	3.2	2.8	4.0	3.9	7.4	11.1	5.7	3.2	7.1	
Cancer salon, Peer support	1.7	1.8	-	2.8	1.3	2.4	1.6	3.7	-	-	2.7	
Other	5.8	6.5	6.5	11.1	5.3	6.3	4.9	3.7	8.6	3.2	4.5	
No specific issues need for consultation	21.7	25.6	35.5	13.9	21.3	28.3	17.2	11.1	11.4	9.7	25.0	
No response	4.2	4.0	9.7	-	4.0	3.9	4.5	3.7	2.9	3.2	6.3	

Currently wanted information

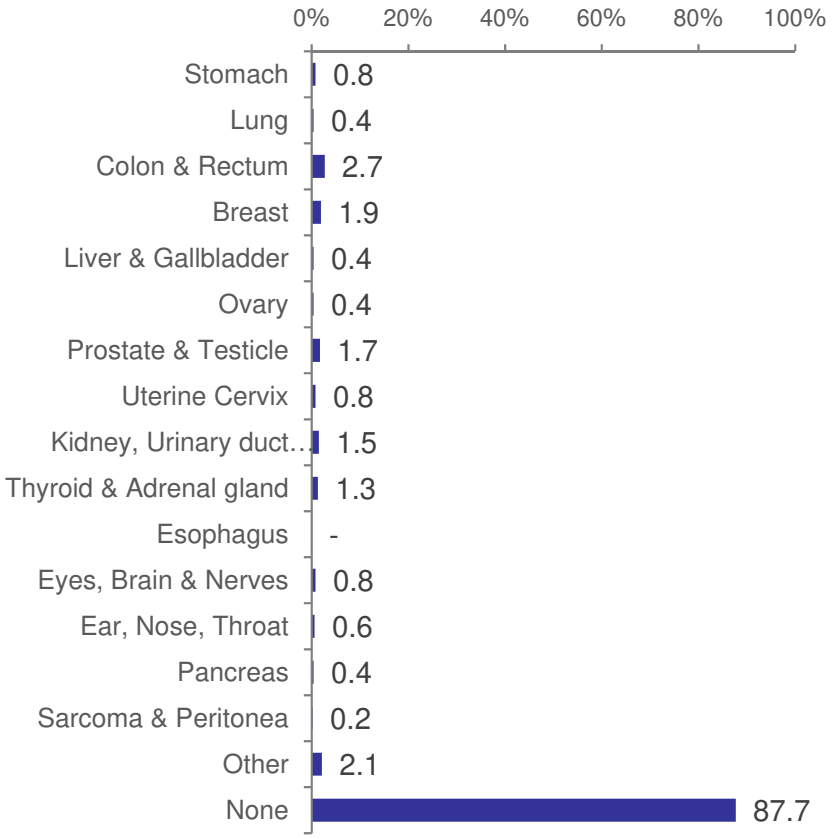
- Male patients, especially the younger group in their 20s-40s, tend to seek information about “New drugs,” “New treatments,” and “Efficacy of drugs.” Female patients in their 50s and 60s tend to look for “Personal experiences from other patients with CML.” Men tend to seek new information such as “New drugs” and “New treatments,” while women tend to ask for information such as “Personal experience stories.”



Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40a	50s	Over 60	
(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
57.4	57.0	64.5	69.4	61.3	49.6	57.8	51.9	57.1	64.5	55.4	(%)
21.3	21.7	32.3	27.8	22.7	18.1	20.9	22.2	8.6	25.8	22.3	
24.2	24.5	29.0	44.4	25.3	18.1	23.8	22.2	20.0	30.6	21.4	
36.1	39.4	58.1	63.9	40.0	28.3	32.4	44.4	48.6	33.9	23.2	
41.1	44.0	54.8	63.9	45.3	36.2	37.7	44.4	45.7	45.2	27.7	
18.8	20.9	32.3	30.6	16.0	18.9	16.4	25.9	17.1	16.1	14.3	
36.7	36.5	48.4	44.4	34.7	31.5	36.9	25.9	37.1	38.7	38.4	
31.3	31.0	41.9	44.4	34.7	22.0	31.6	25.9	37.1	33.9	29.5	
26.1	26.7	41.9	38.9	29.3	18.1	25.4	22.2	25.7	38.7	19.6	
8.3	7.6	9.7	5.6	9.3	7.1	9.0	7.4	2.9	12.9	9.8	
27.4	24.9	29.0	33.3	25.3	20.5	30.3	25.9	17.1	35.5	31.3	
8.6	8.7	16.1	8.3	10.7	4.7	8.6	11.1	5.7	8.1	8.9	
4.8	5.1	3.2	2.8	4.0	7.1	4.5	3.7	2.9	1.6	7.1	
2.9	2.9	9.7	2.8	2.7	1.6	2.9	3.7	14.3	-	-	
3.8	2.2	3.2	2.8	-	3.1	5.7	14.8	5.7	6.5	1.8	
5.8	7.9	6.5	5.6	8.0	9.4	3.3	-	2.9	1.6	5.4	
1.7	2.2	-	-	1.3	3.1	1.2	-	2.9	-	1.8	

Cancer experience other than CML

- 12% of patients with CML experienced cancers other than CML.
- Other cancers include “Colon and Rectum” (3%), “Breast” (2%), “Prostate and Testicle” (2%), and “Kidney, Urinary duct and Bladder” (2%), but no distinctive trend is seen.



	Grand total	Male total	20s/30s	40s	50s	Over 60	Female total	20s/30s	40a	50s	Over 60	
n	(521)	(277)	(31)	(36)	(75)	(127)	(244)	(27)	(35)	(62)	(112)	
	0.8	1.1	-	-	-	2.4	0.4	-	-	-	0.9	(%)
	0.4	0.4	-	-	-	0.8	0.4	-	-	-	0.9	
	2.7	2.9	-	2.8	1.3	4.7	2.5	-	2.9	1.6	3.6	
	1.9	-	-	-	-	-	4.1	-	2.9	3.2	6.3	
	0.4	0.4	-	-	-	0.8	0.4	-	2.9	-	-	
	0.4	-	-	-	-	-	0.8	-	-	-	1.8	
	1.7	3.2	-	-	2.7	5.5	-	-	-	-	-	
	0.8	-	-	-	-	-	1.6	-	-	4.8	0.9	
	1.5	2.5	-	-	-	5.5	0.4	-	-	-	0.9	
	1.3	0.4	-	-	-	0.8	2.5	-	-	-	5.4	
	-	-	-	-	-	-	-	-	-	-	-	
	0.8	1.1	-	-	-	2.4	0.4	-	-	-	0.9	
	0.6	1.1	-	-	-	2.4	-	-	-	-	-	
	0.4	0.7	-	-	-	1.6	-	-	-	-	-	
	0.2	0.4	-	-	-	0.8	-	-	-	-	-	
	2.1	2.5	3.2	-	1.3	3.9	1.6	-	2.9	1.6	1.8	
	87.7	89.2	96.8	97.2	94.7	81.1	86.0	100.0	91.4	90.3	77.7	