

**KNOW
YOUR
CML**

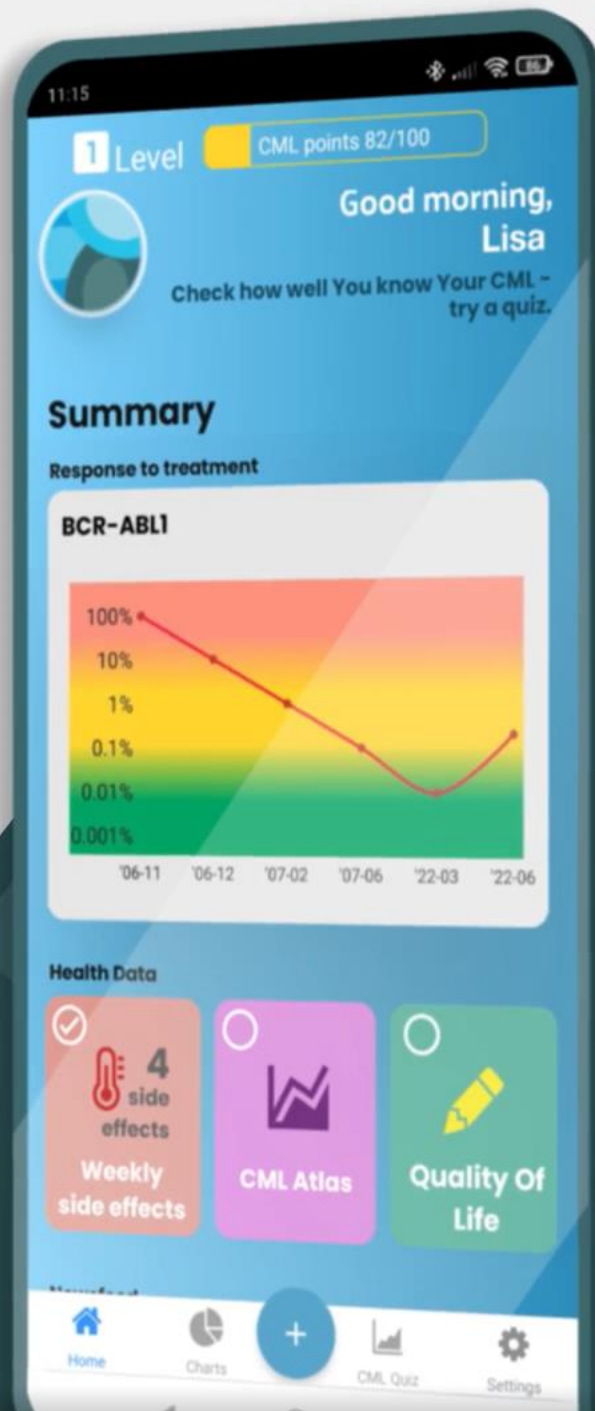
Developed by CML Advocates Network



CML ADVOCATES
NETWORK

▶ **Patient Generated Evidence**

Šarūnas Narbutas
2023-11-05



ACCESS THE WEBSITE
cmlregistry.com



Download on the
App Store



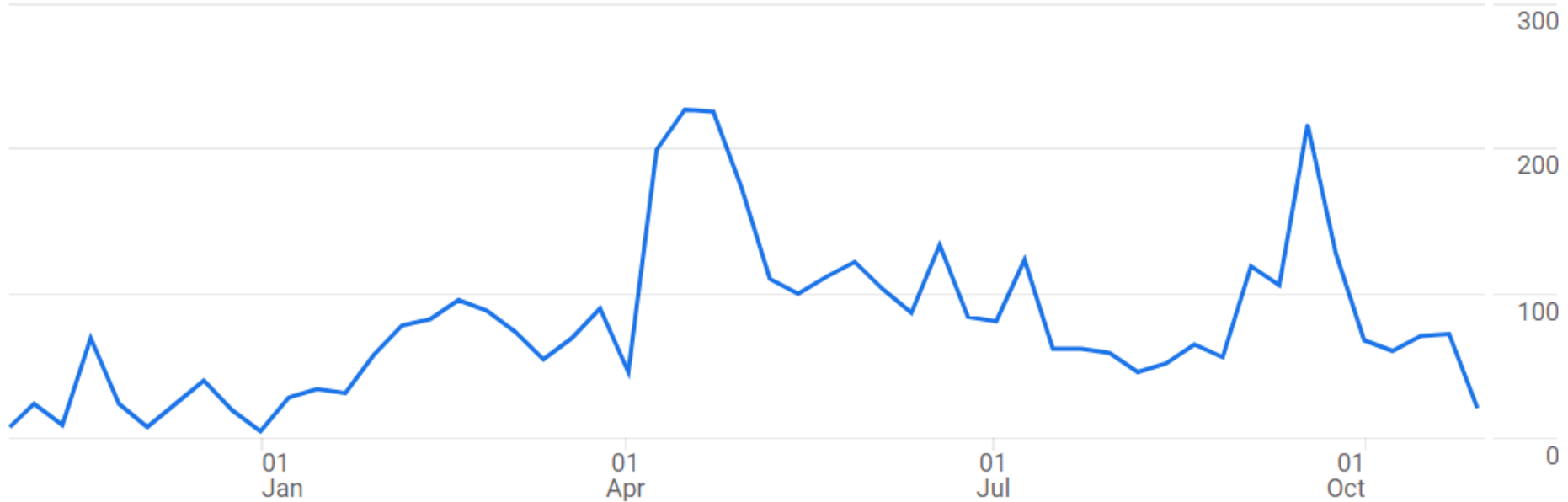
GET IT ON
Google Play

free of charge

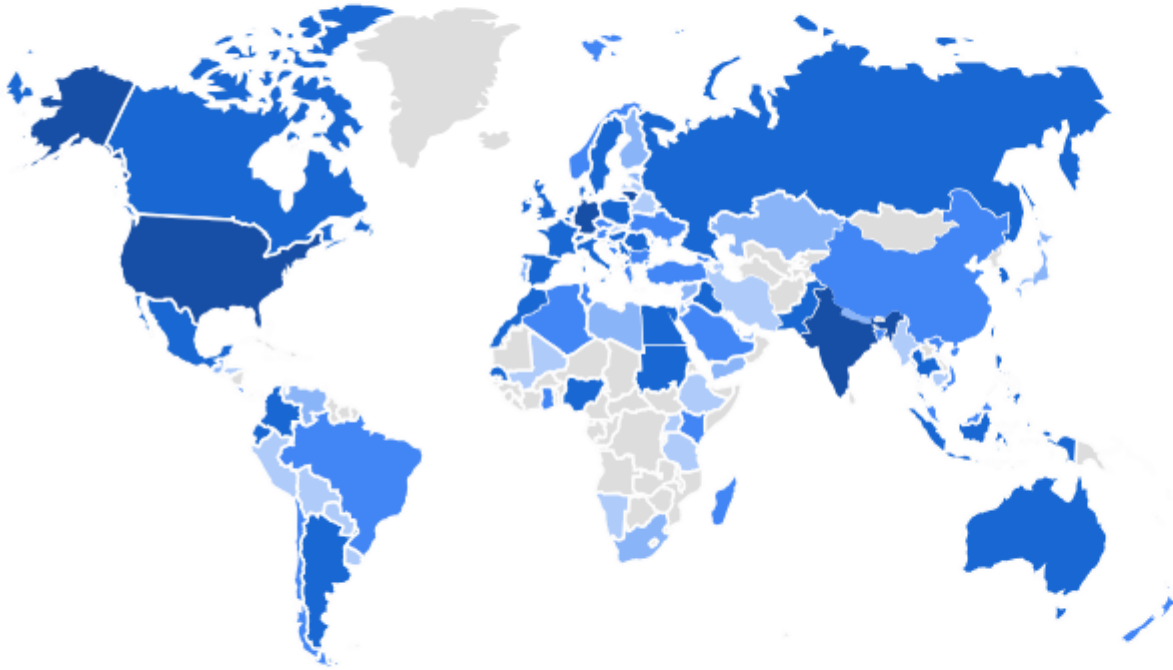
ad-free

Number of users during past 12 months (1 442 unique active users)

Users: 2.6K New users: 2.5K Average engagement time: 23m 46s Period: Oct 31, 2022 – Oct 31, 2023



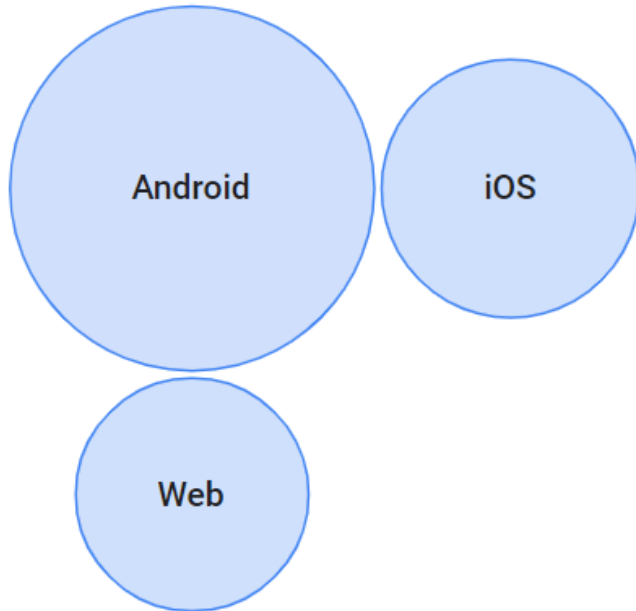
Users ▼ by Country



<u>COUNTRY</u>	<u>USERS</u>
United States	609
India	356
Lithuania	199
Germany	181
Israel	113
Philippines	73
Morocco	70

[View countries](#) →

Users by Platform



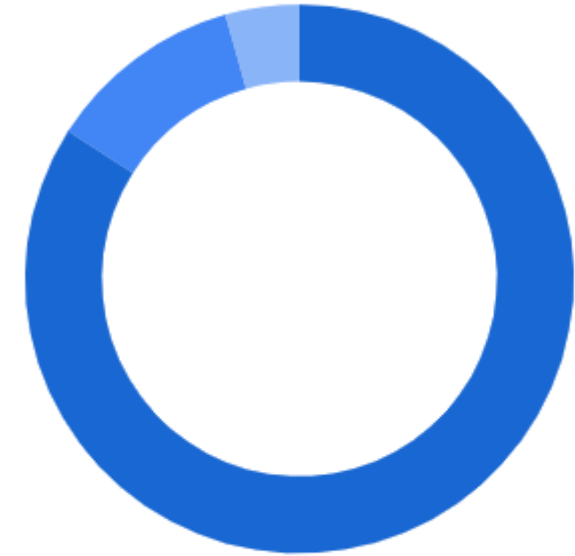
ANDROID
52.3%

IOS
26.3%

WEB
21.4%

[View platforms →](#)

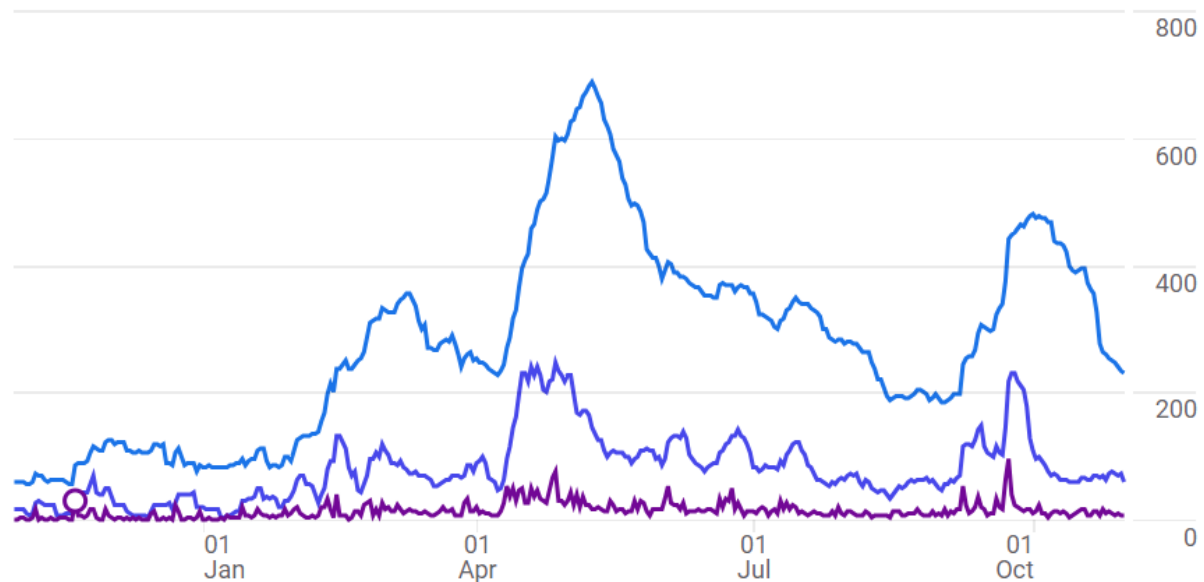
Users by Device category



MOBILE 84.0% DESKTOP 11.6% TABLET 4.4%

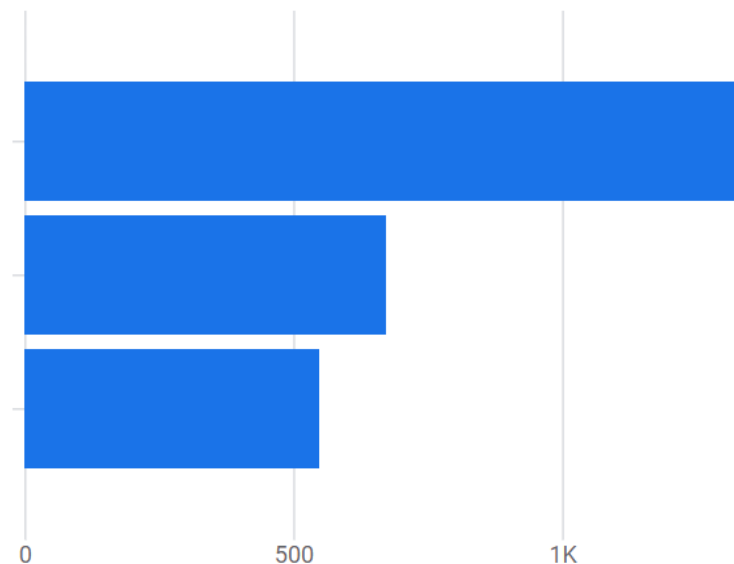
[View device categories →](#)

User activity over time



● 30 DAYS
229
● 7 DAYS
59
● 1 DAY
5

Users by Platform



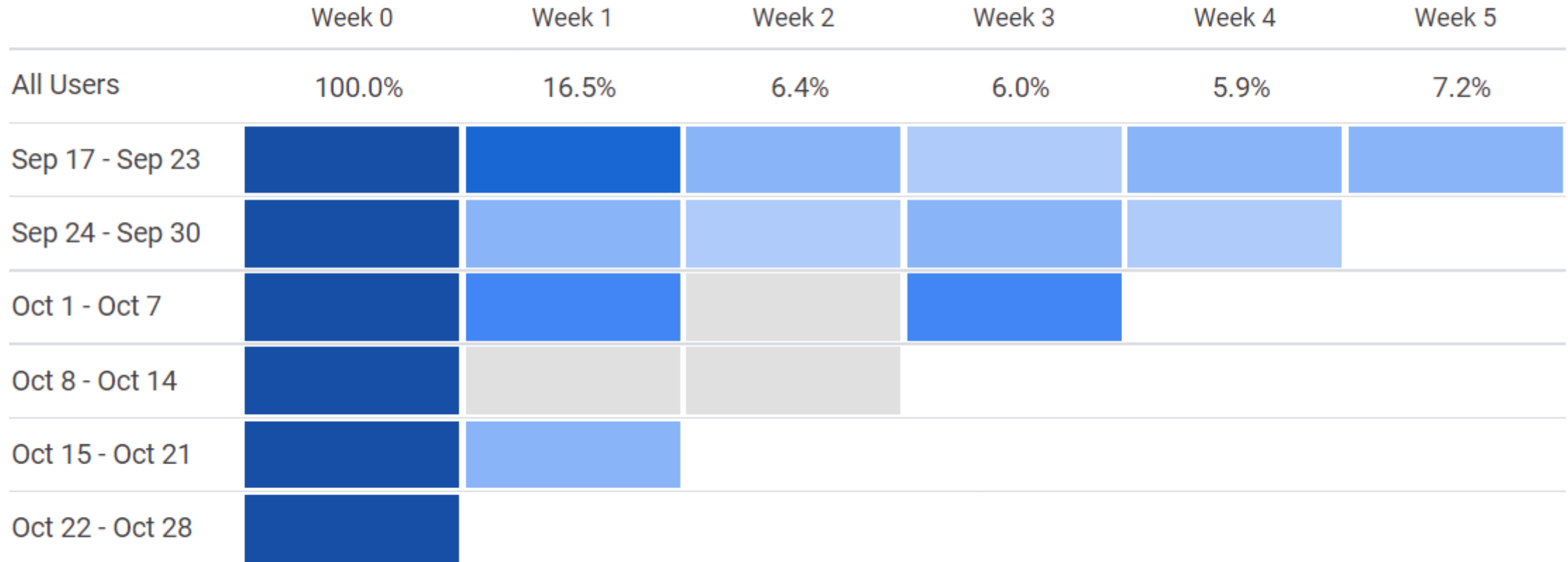
Search...

Rows per page: 10 1-3 of 3

Platform	Users	New users	Engaged sessions	Engagement rate	Engaged sessions per user	Average engagement time	Event count
	2,562 100% of total	2,461 100% of total	5,031 100% of total	75.77% Avg 0%	1.96 Avg 0%	23m 46s Avg 0%	163,398 100% of total
1 Android	1,341	1,244	3,040	80.23%	2.27	20m 21s	82,608
2 iOS	673	675	1,401	78.62%	2.08	48m 07s	68,094
3 web	548	542	545	53.48%	0.99	2m 14s	12,696

User activity by cohort

Based on device data only

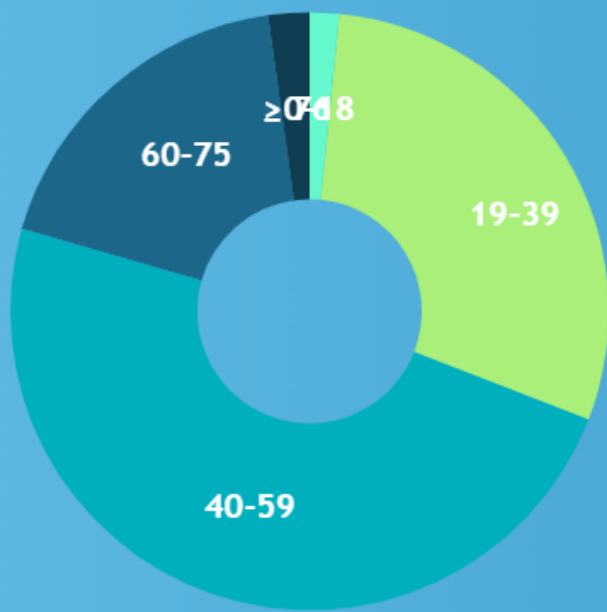


6 weeks ending Oct 31

[View retention](#) →

Snapshot of database analysis as of 2023-11-01





N = 915

CML Age groups by CML Registry data:

Filter community answers by:

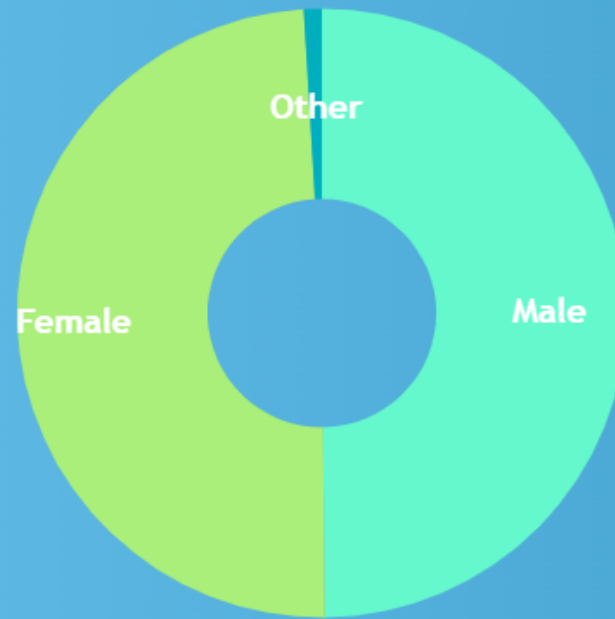
My Gender

My Illness Duration

Treatment Type

CML registry general data

- 0-18: 2%
- 19-39: 29%
- 40-59: 49%
- 60-75: 18%
- ≥76: 2%



N = 915

CML Registry groups by sex:

Filter community answers by:

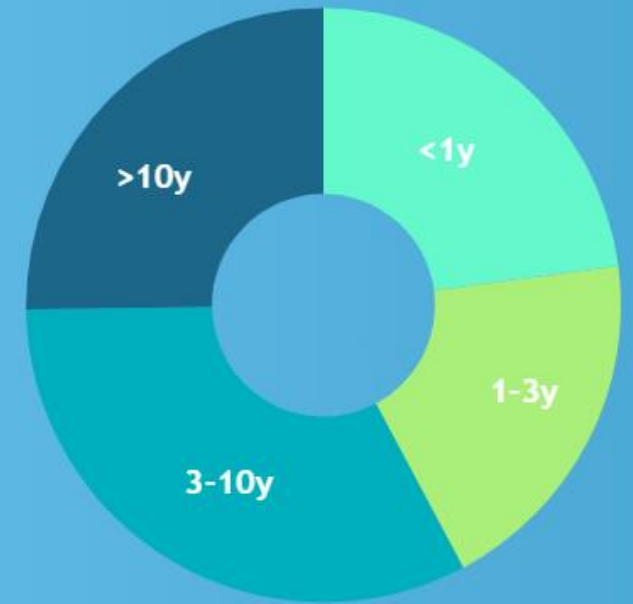
My Age

My Illness Duration

Treatment Type

CML registry general data

- Male: 50%
- Female: 49%
- Other: 1%



N = 915

CML groups by time since diagnosis:

Filter community answers by:

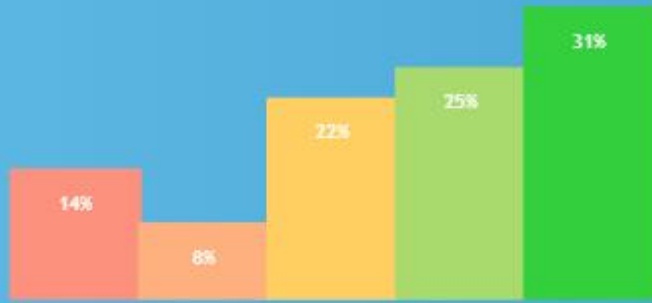
My Age

My Gender

Treatment Type

CML registry general data

- Less than a 1 year: 23%
- From 1 to 3 years: 19%
- From 3 to 10 years: 33%
- More than a 10 years: 25%



N = 628

CML registry PCR level data:

Filter community answers by:

My Age

My Gender

My Illness Duration

CML registry general data

- 10-100%: 14%
- 1-10%: 8%
- 0.1%-1% MMR: 22%
- 0.001-0.32% MR4: 25%
- less than 0.001% MR5: 31%

CML groups by treatment:

N = 851

Filter community answers by:

My Age

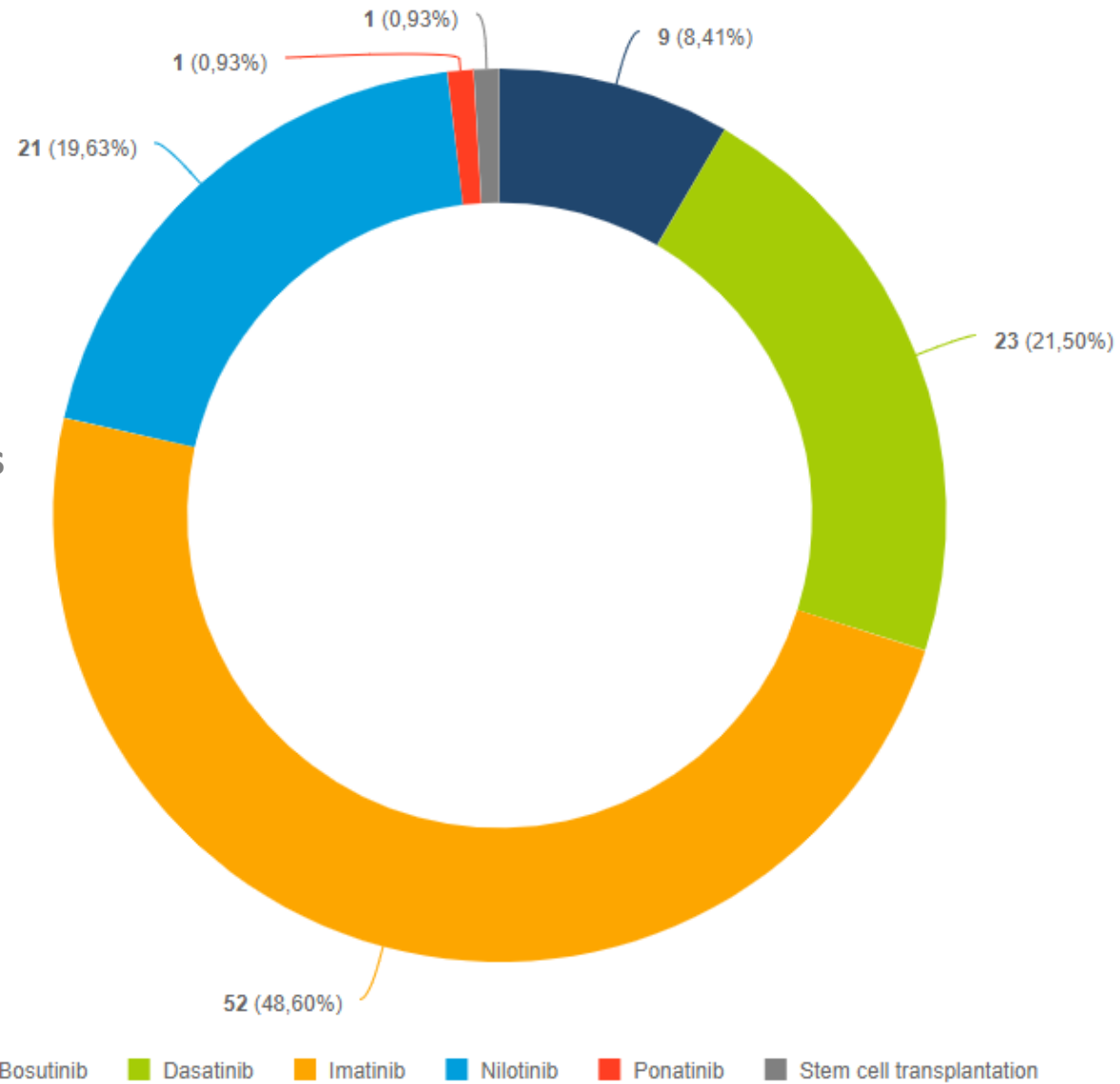
My Gender

My Illness Duration

CML registry general data

- Imatinib (Glivec®): 31%
- Generic Imatinib: 13%
- Nilotinib (Tasigna®): 18%
- Generic Nilotinib: 1%
- Dasatinib (Sprycel®): 21%
- Generic Dasatinib: 4%
- Bosutinib (Bosulif®): 7%
- Ponatinib (Iclusig®): 2%
- Radotinib (Supect®): 0%
- Hydroxyurea: 1%
- Interferon alfa: 0%
- Interferon beta: 0%
- Bone marrow transplantation 2%

Reported side effects under EORTC QLQ-C30 + CML24 (n = 107)



12,6% patients reported side-effects

Total number of patients on specific TKIs as per database:

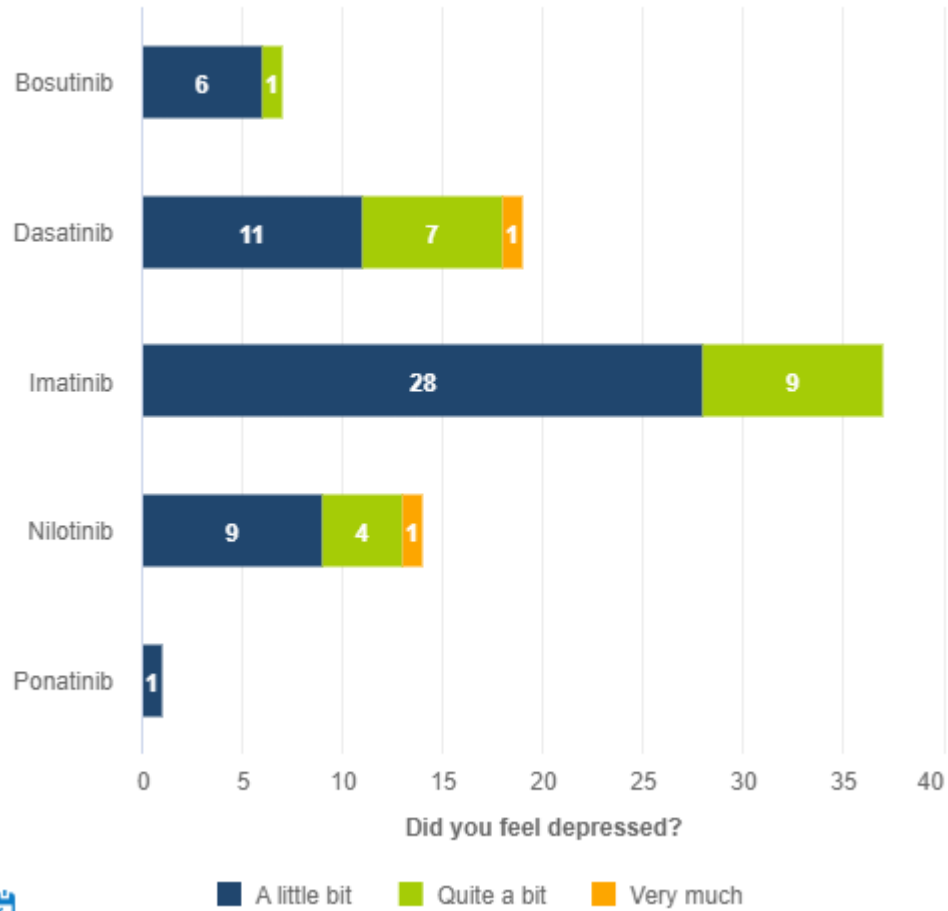
- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)



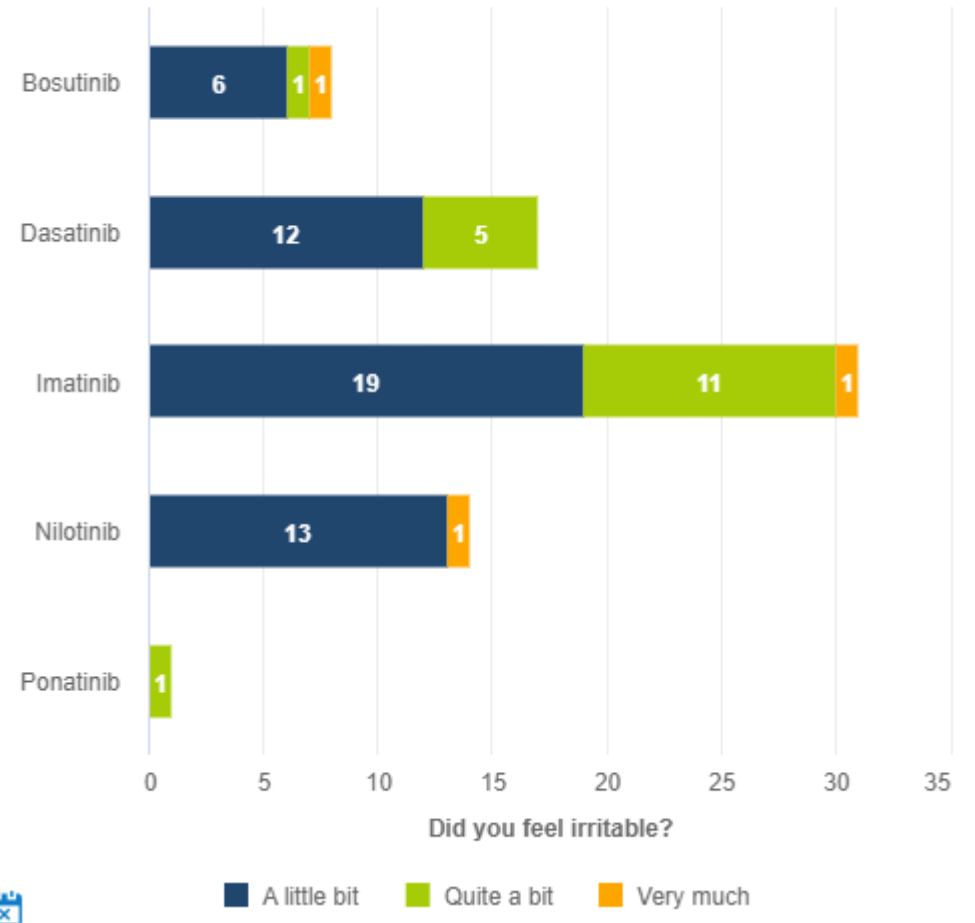
Mental health insights



Did you feel depressed?

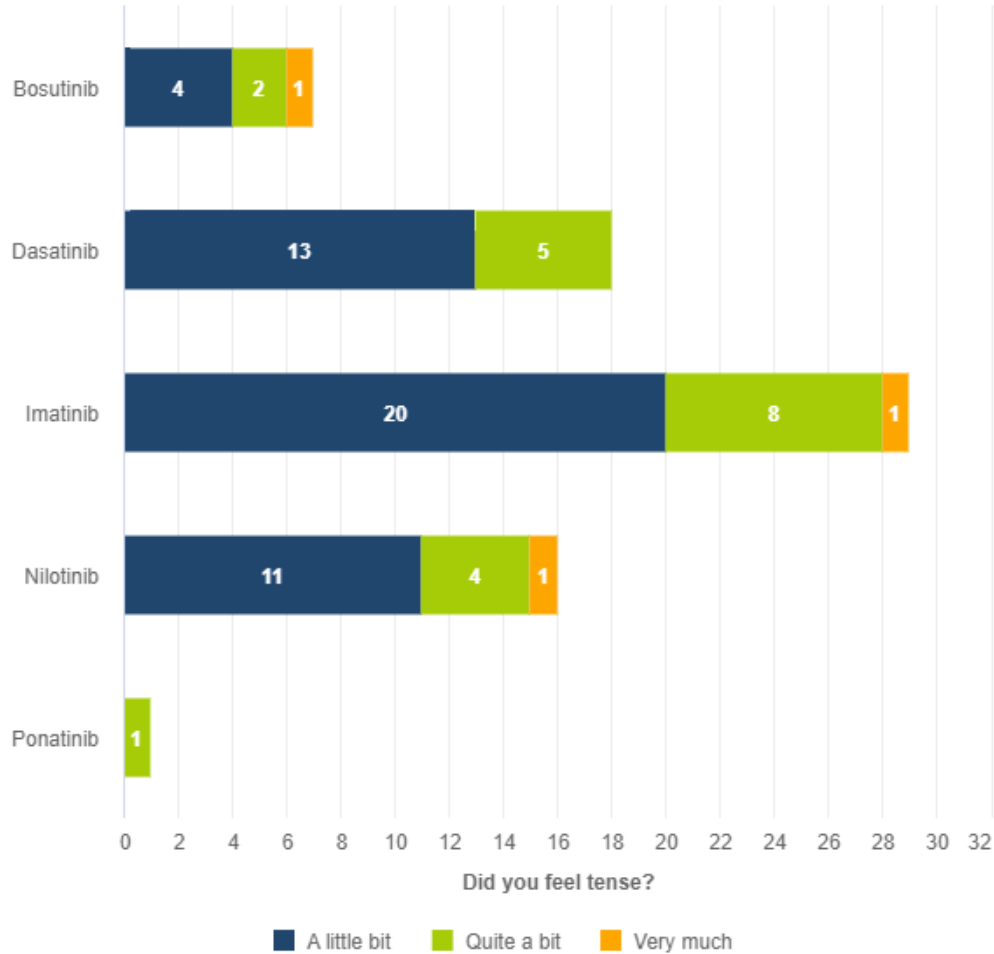


Did you feel irritable?

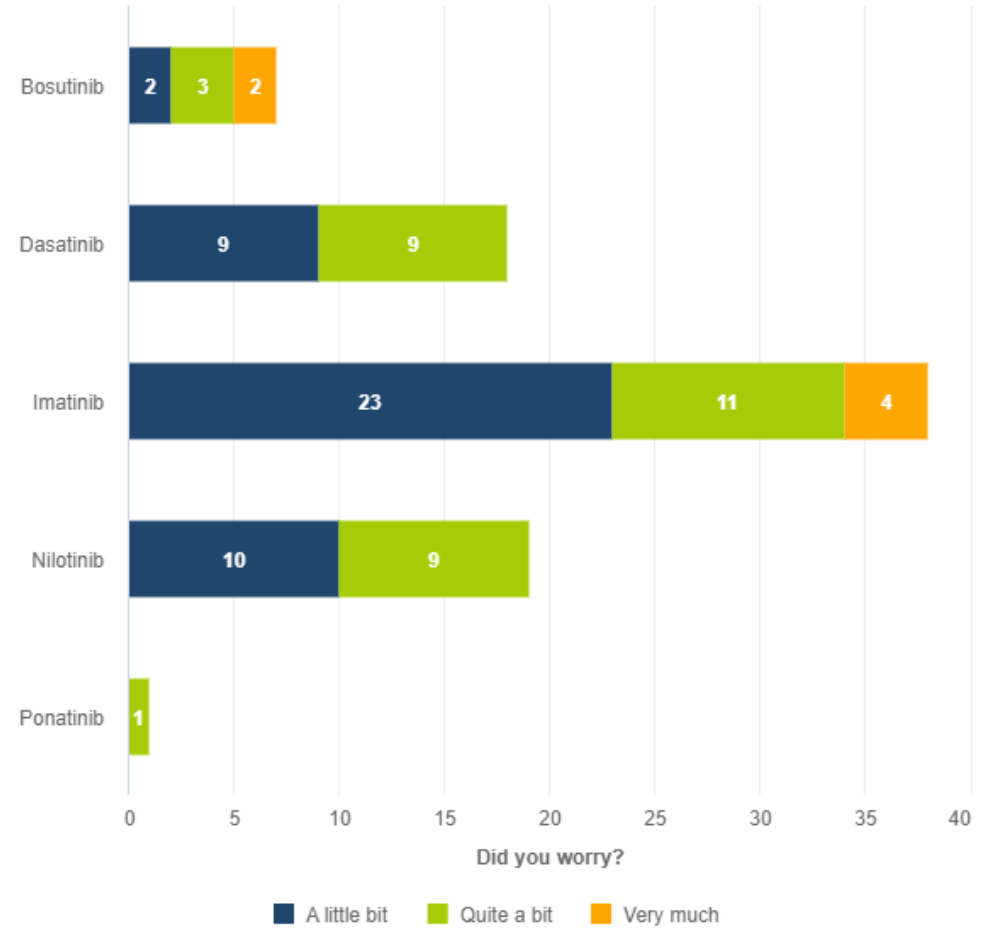




Did you feel tense?



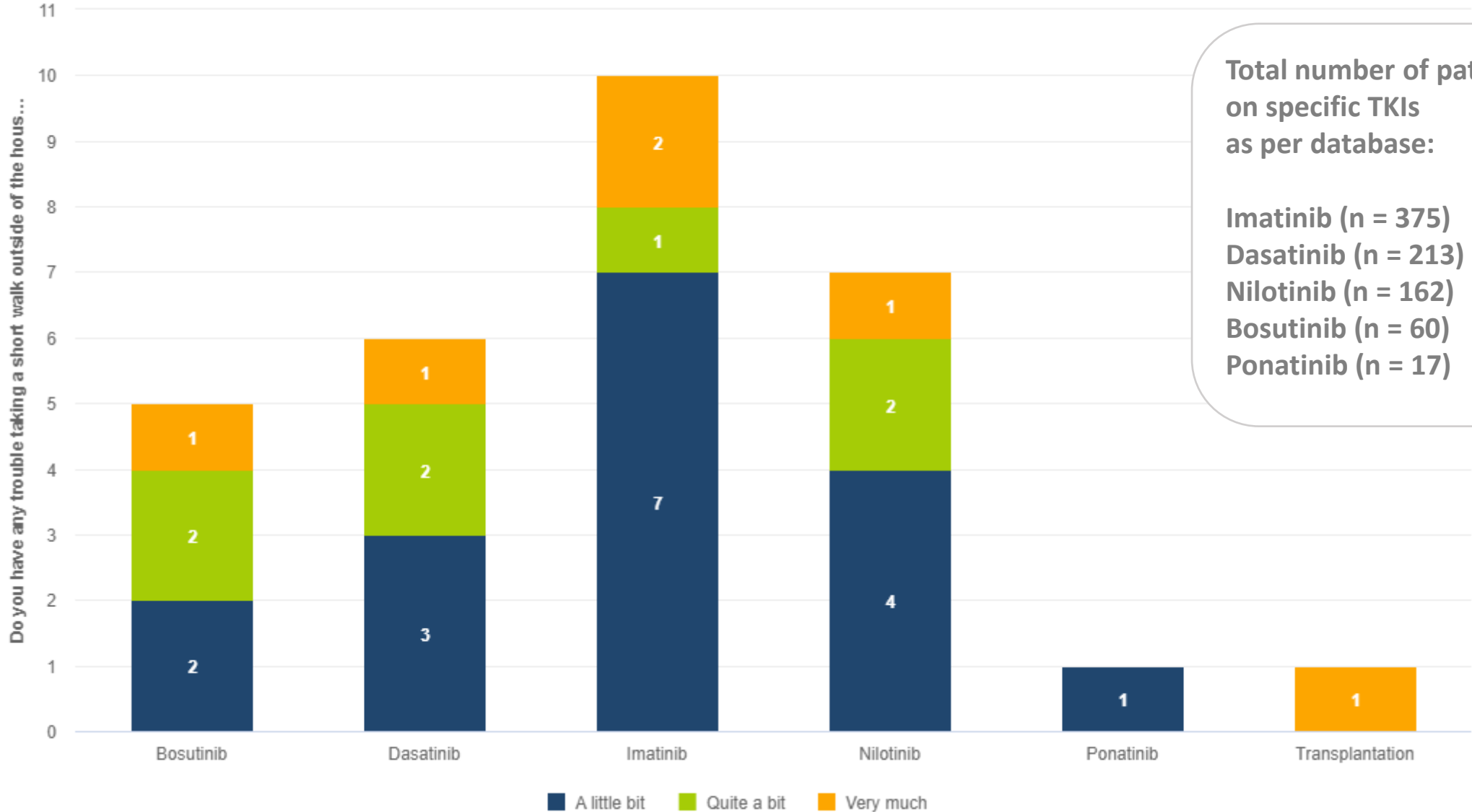
Did you worry?





Fatigue related findings

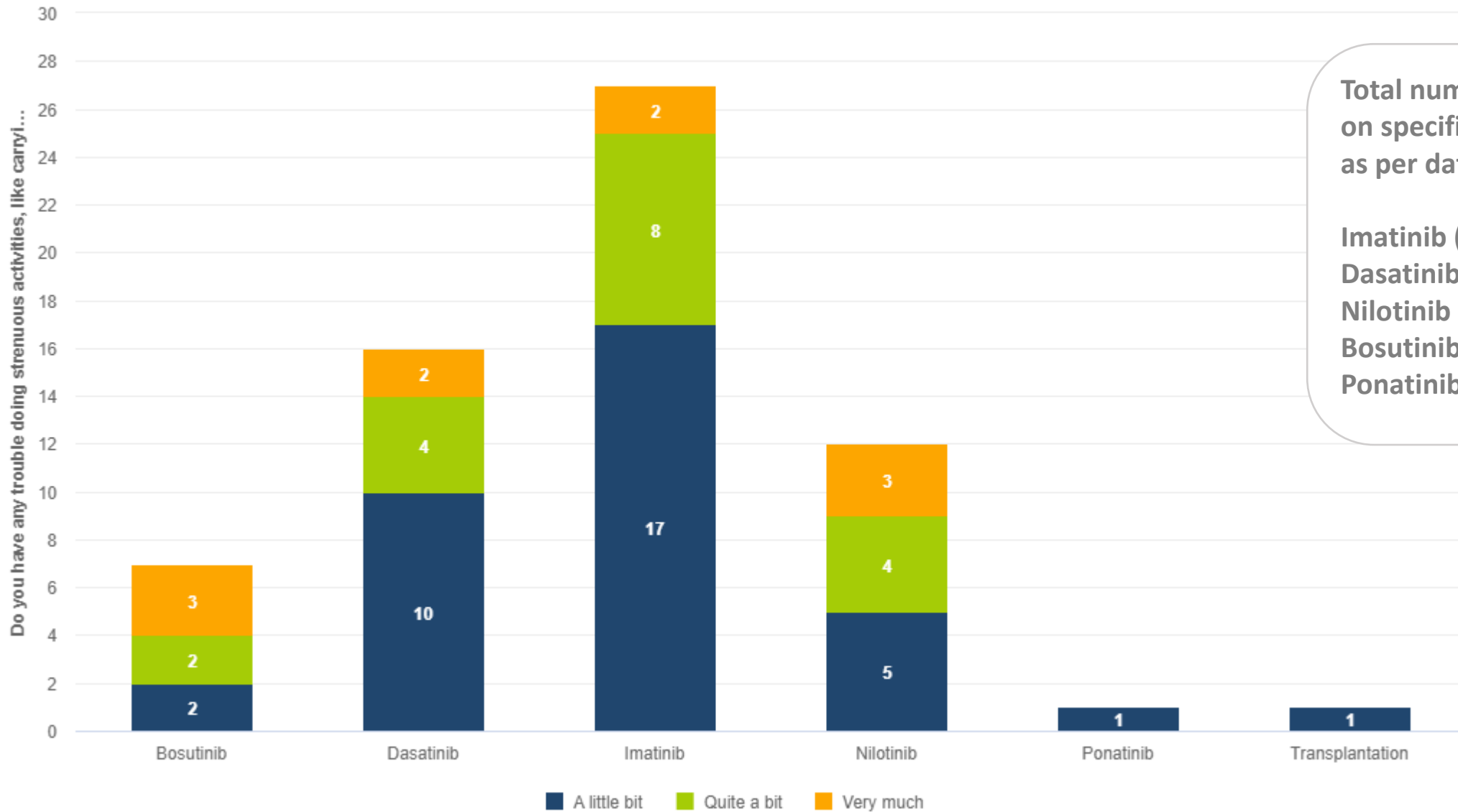
Do you have any trouble taking a short walk outside of the house?



Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

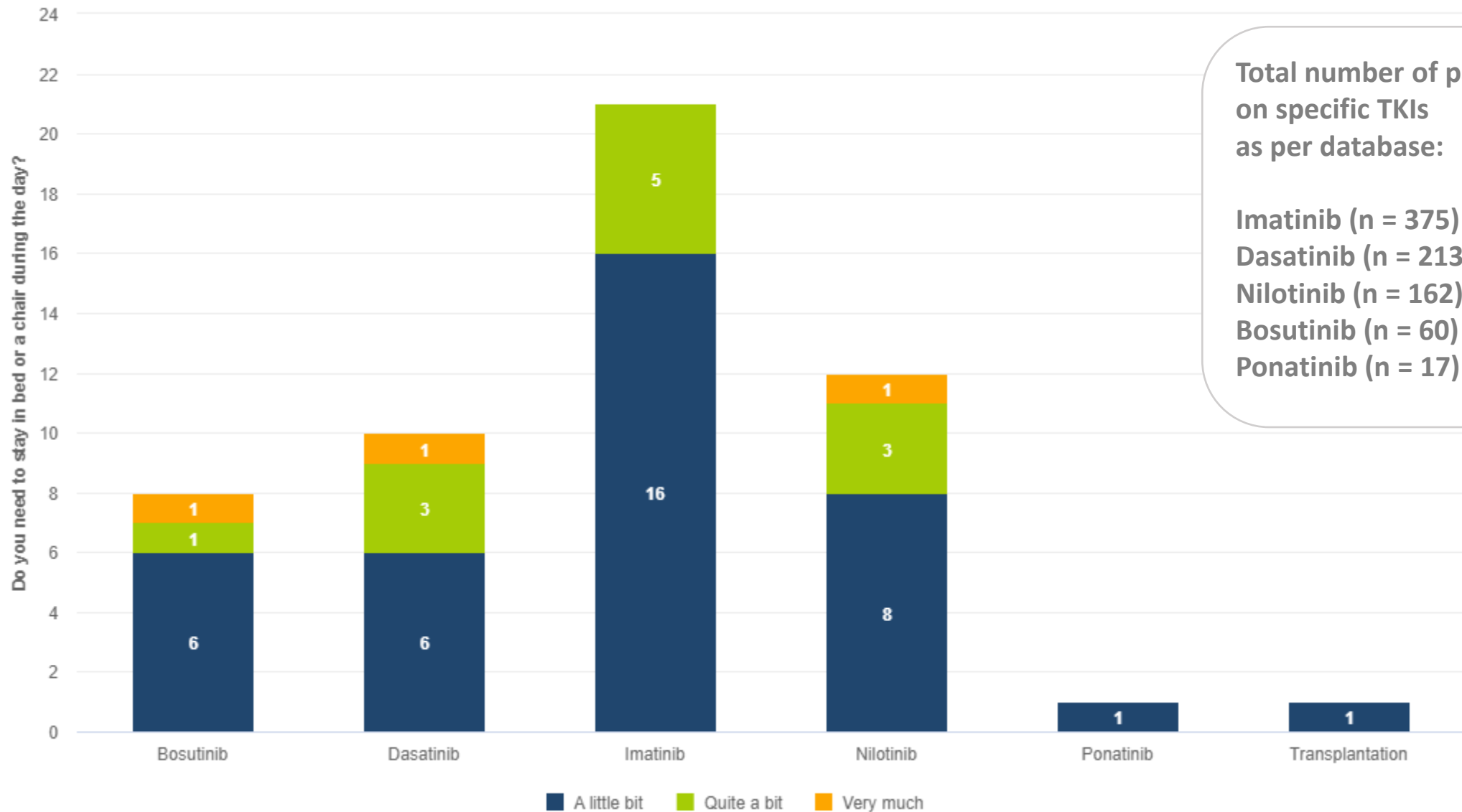
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?



Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

Do you need to stay in bed or a chair during the day?



Total number of patients on specific TKIs as per database:

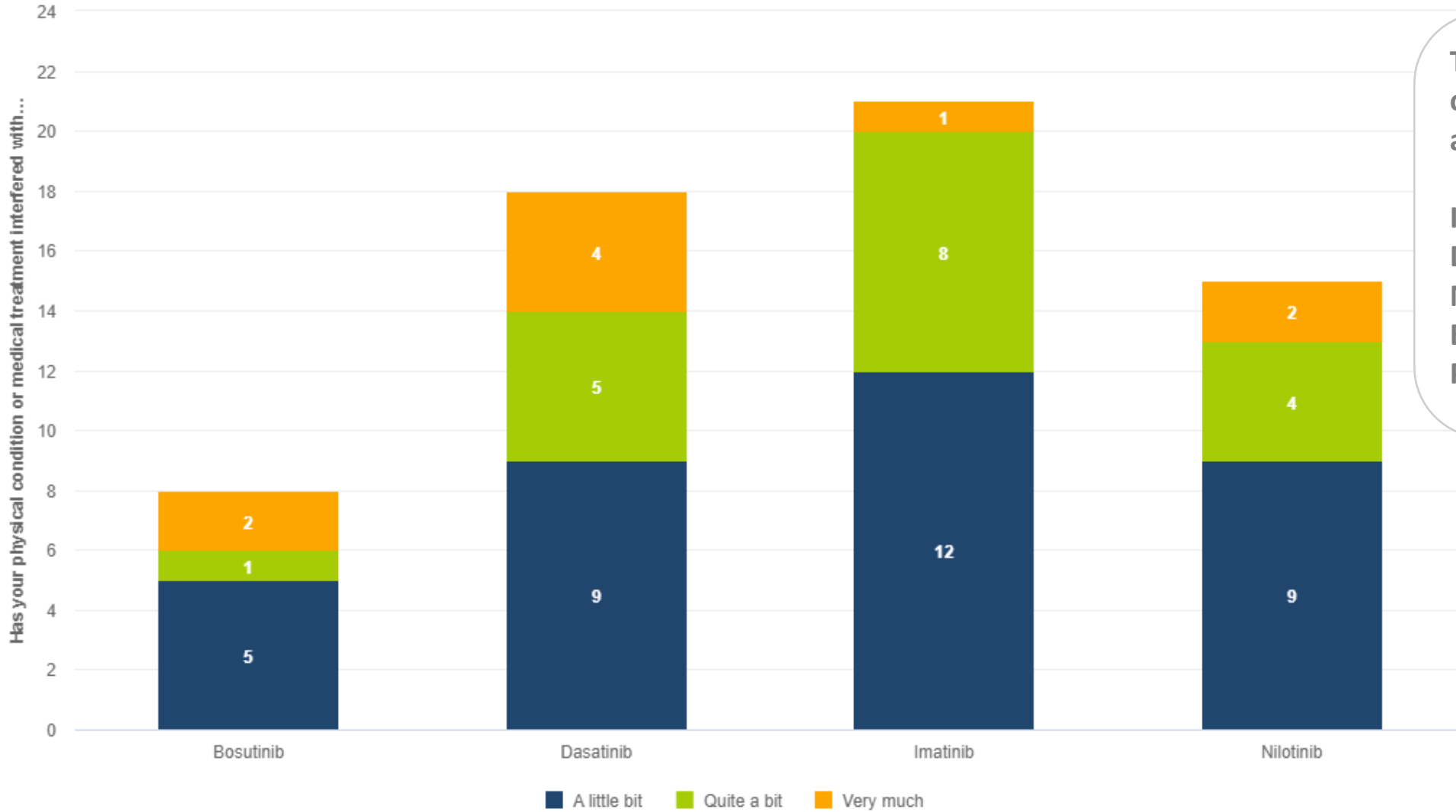
Imatinib (n = 375)
Dasatinib (n = 213)
Nilotinib (n = 162)
Bosutinib (n = 60)
Ponatinib (n = 17)



Impact on social life



Has your physical condition or medical treatment interfered with your social activities?

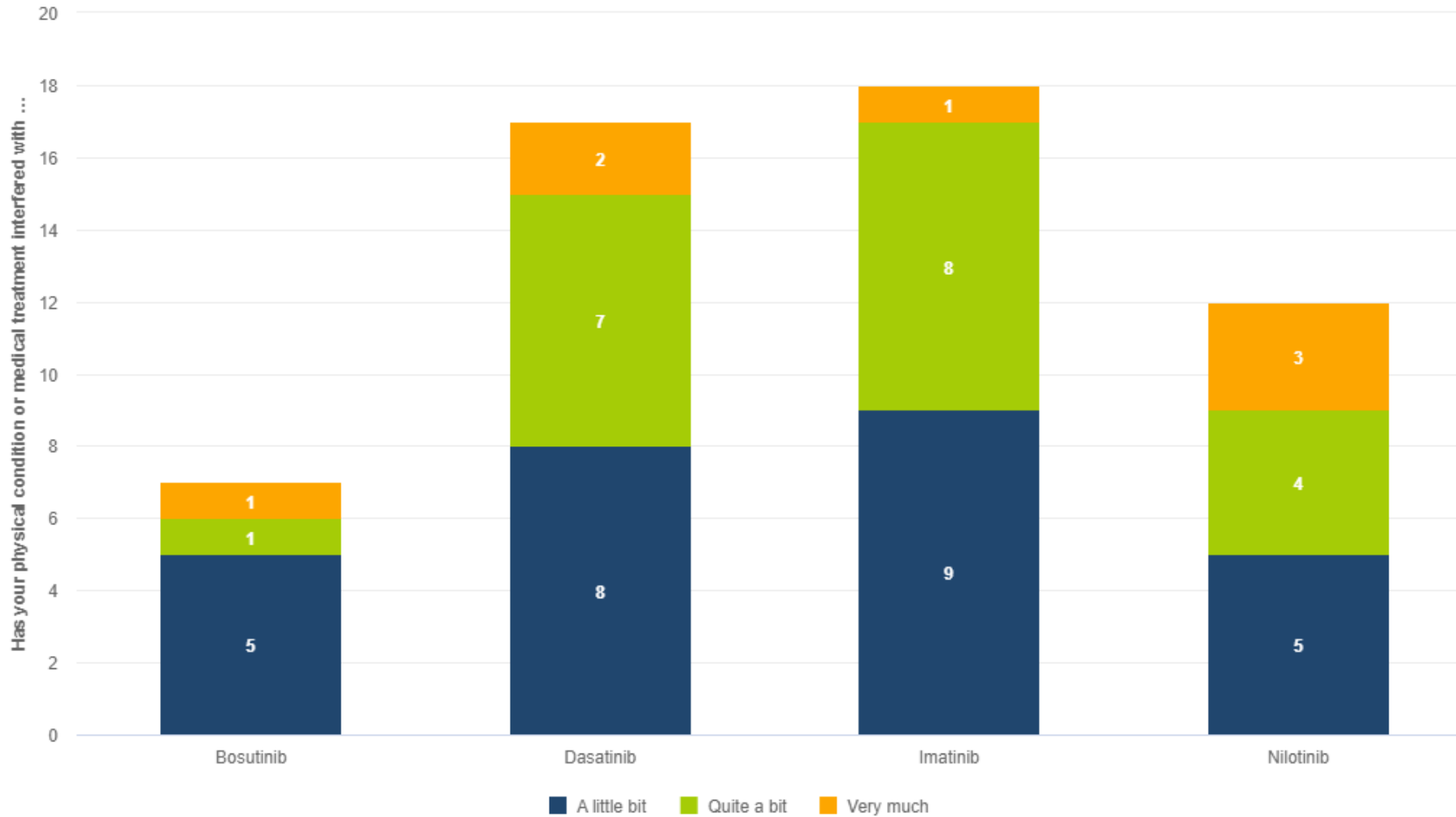


Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)



Has your physical condition or medical treatment interfered with your family life?

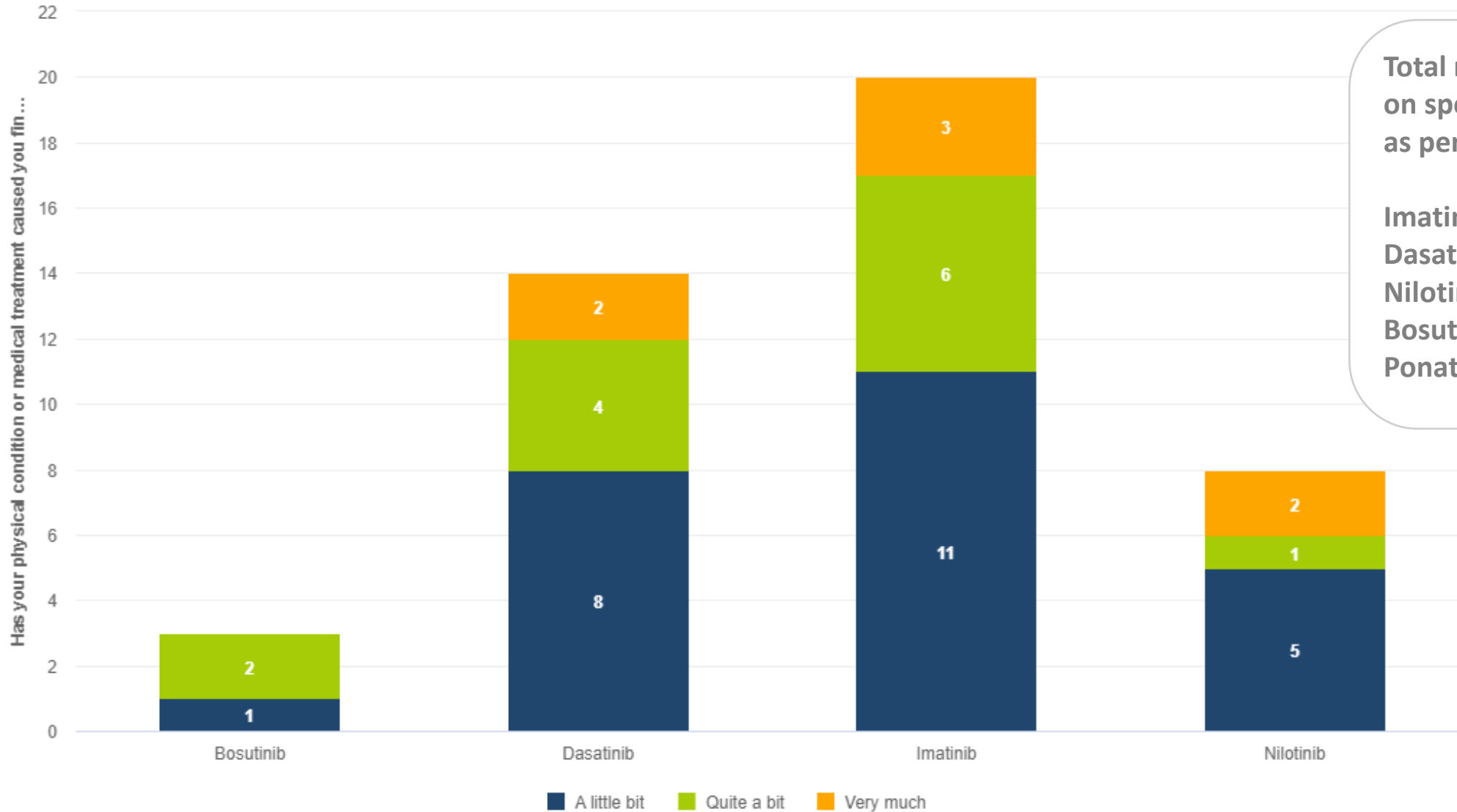


Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)



Has your physical condition or medical treatment caused you financial difficulties?

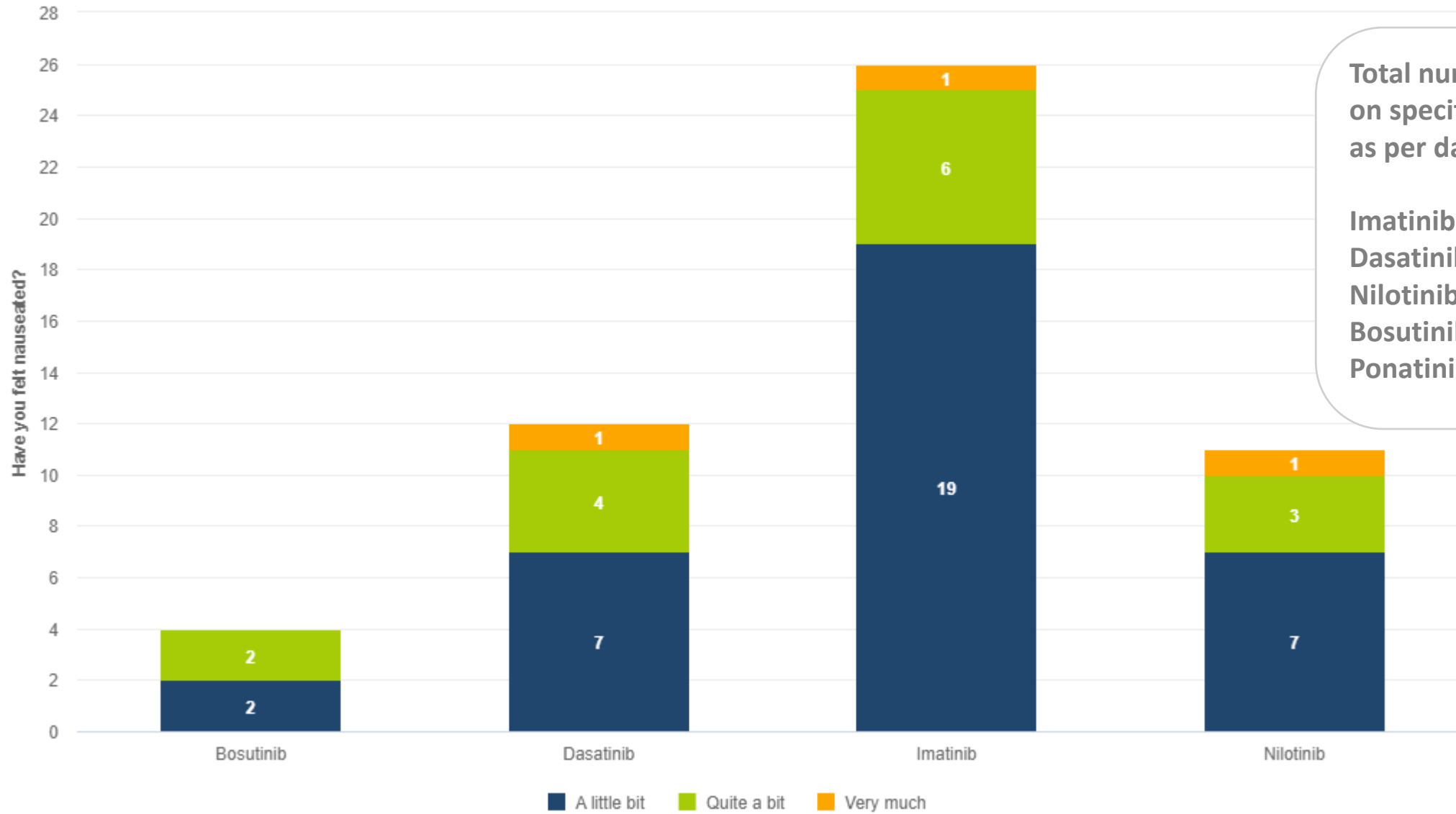


Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

Most frequent side effects

Have you felt nauseated?

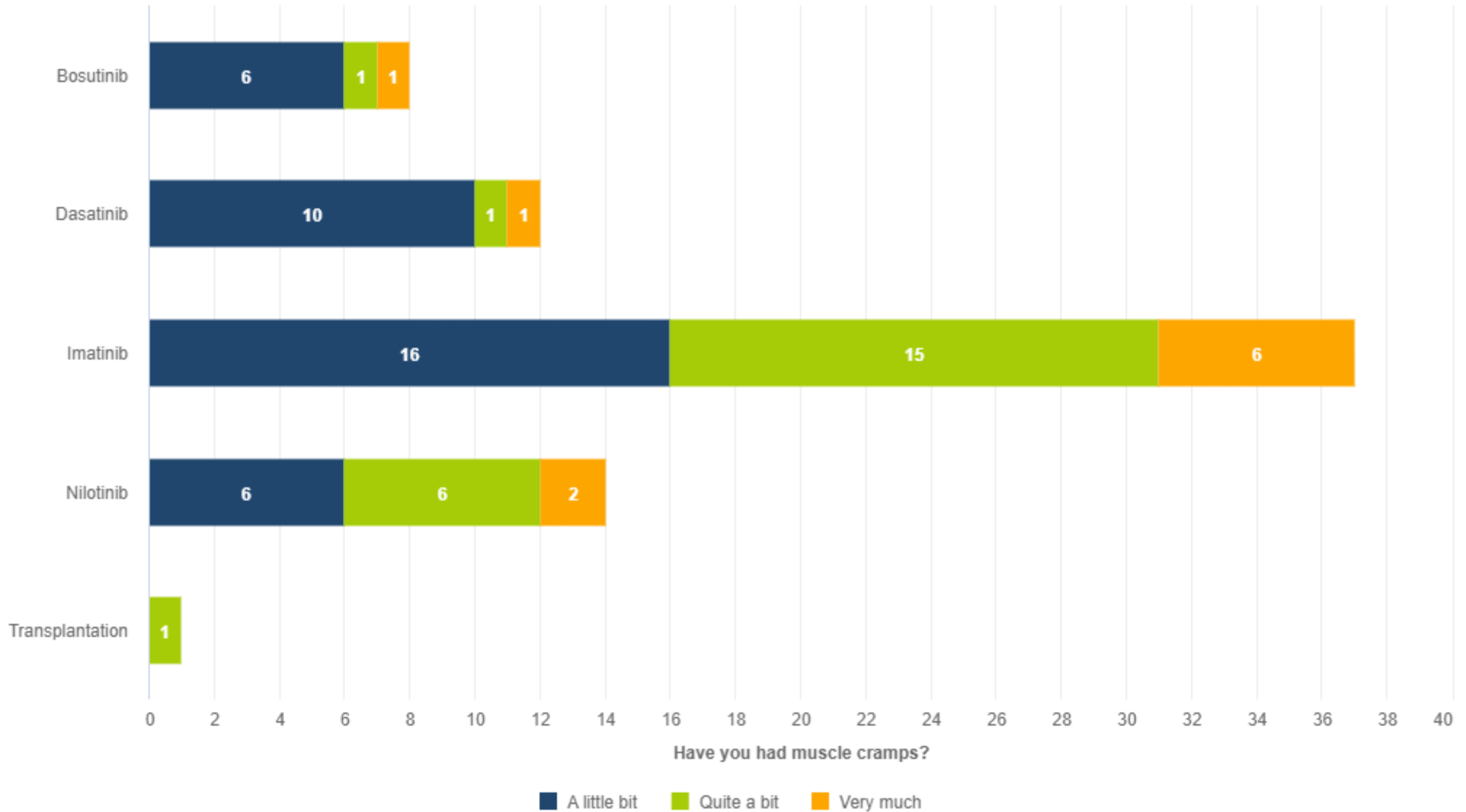


Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

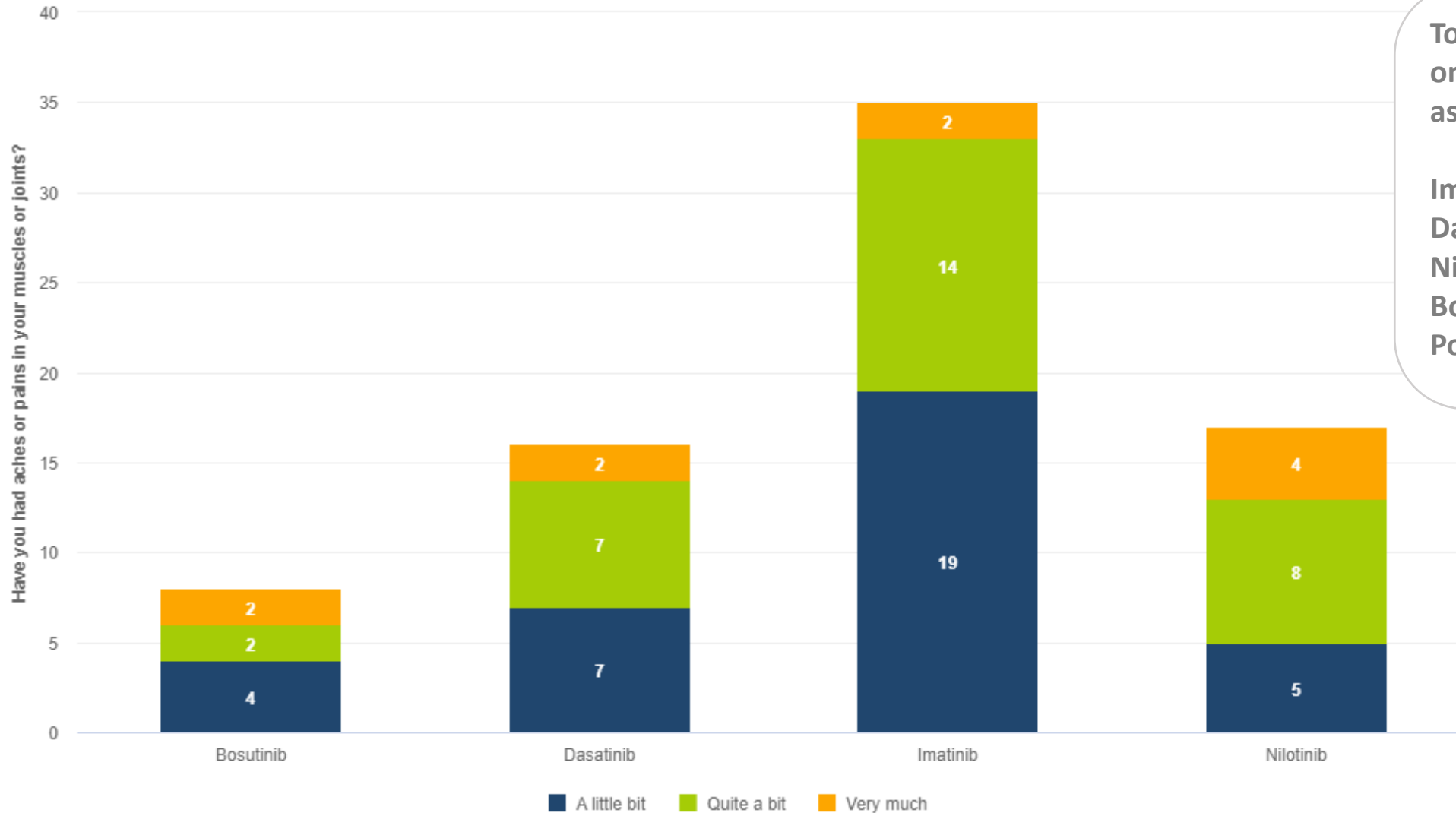


Have you had muscle cramps?





Have you had aches or pains in your muscles or joints?

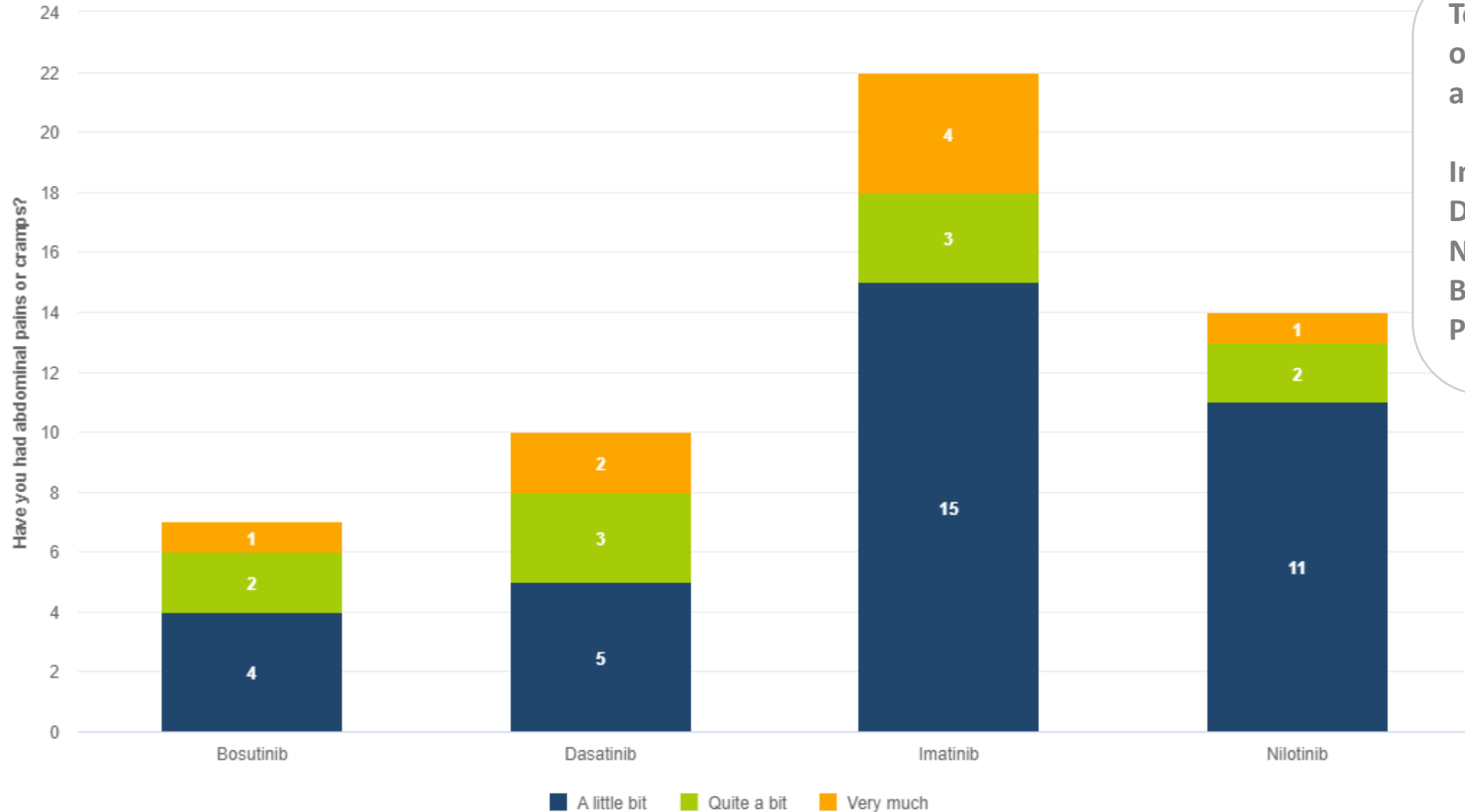


Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)**
- Dasatinib (n = 213)**
- Nilotinib (n = 162)**
- Bosutinib (n = 60)**
- Ponatinib (n = 17)**



Have you had abdominal pains or cramps?

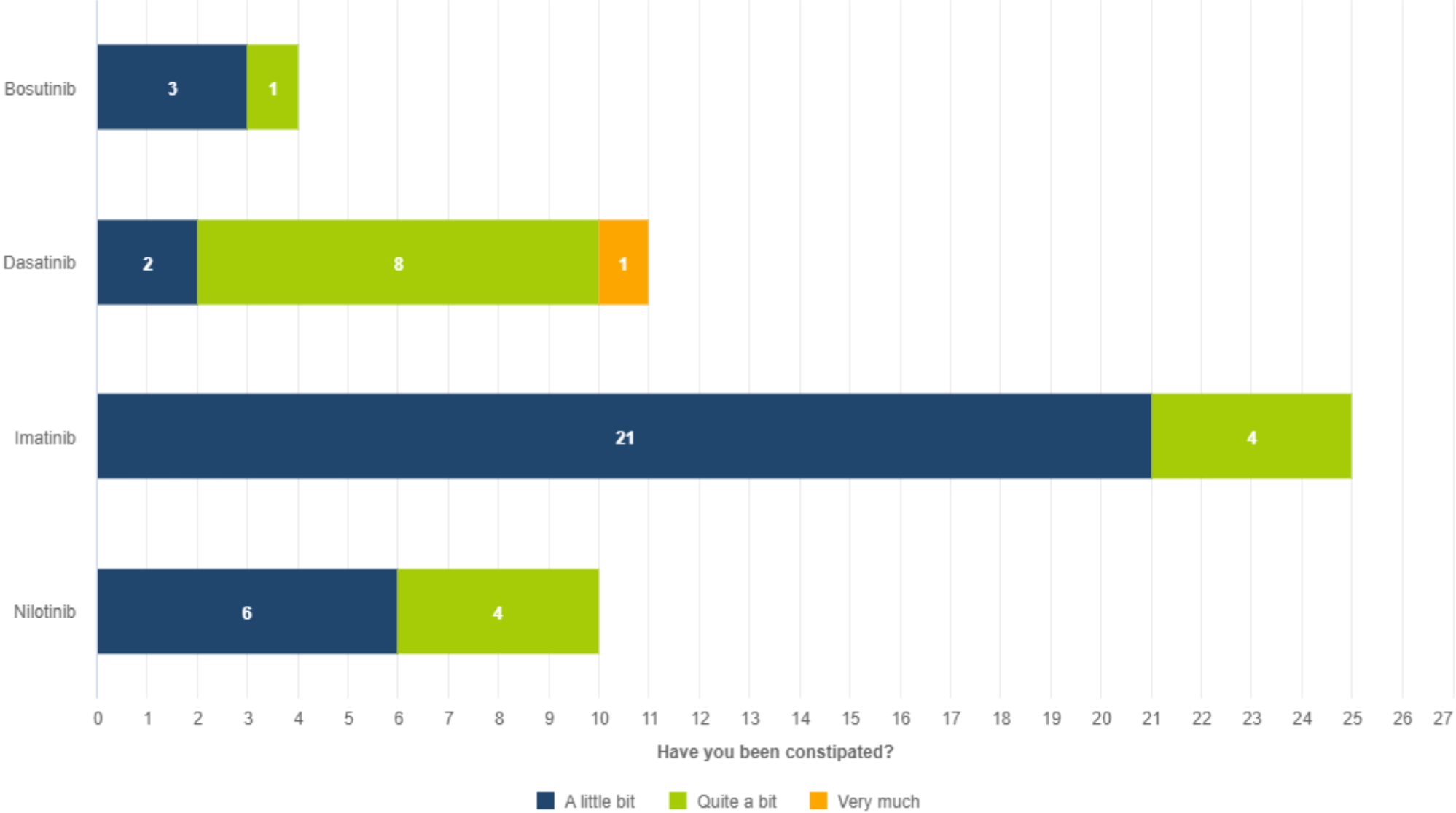


Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

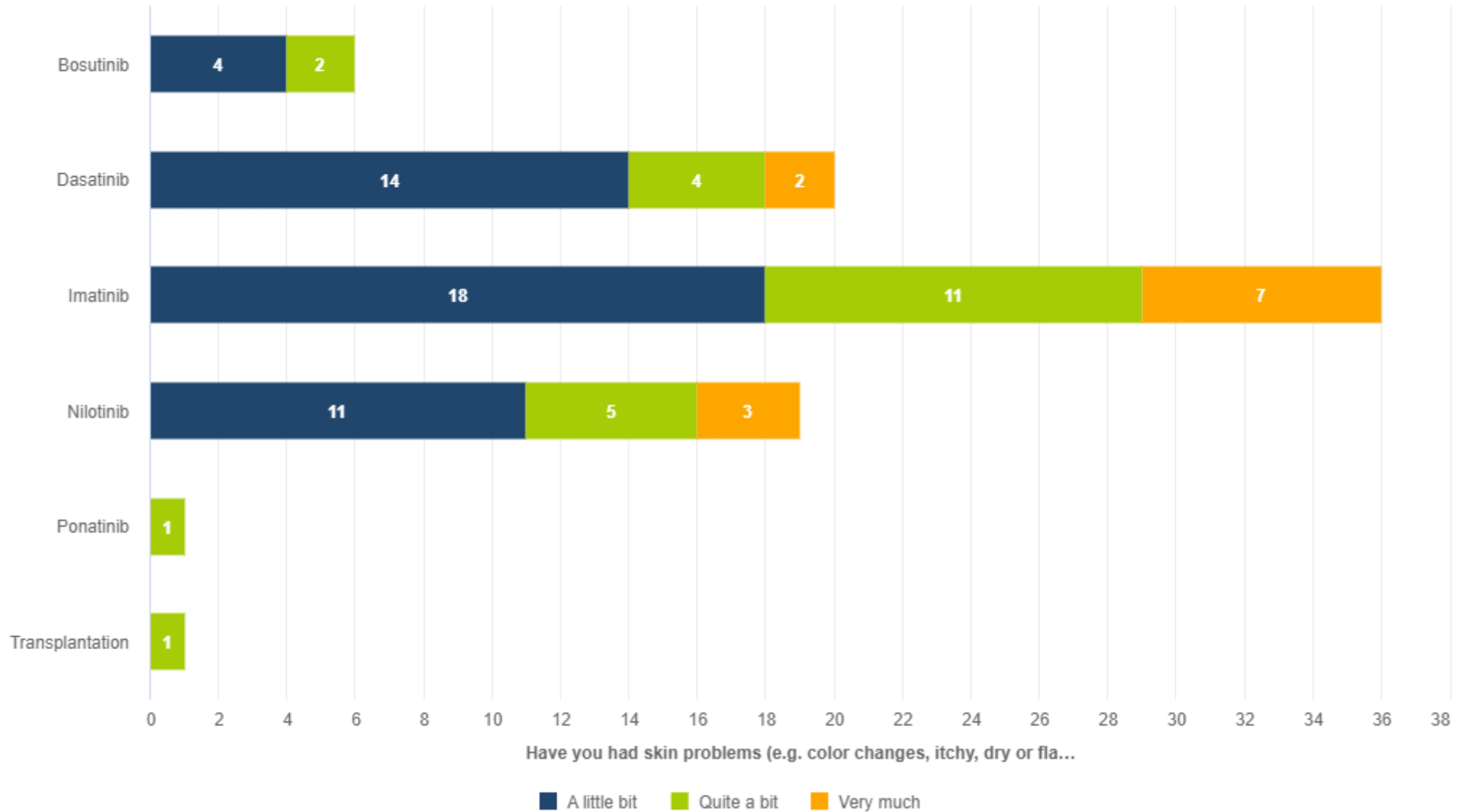


Have you been constipated?

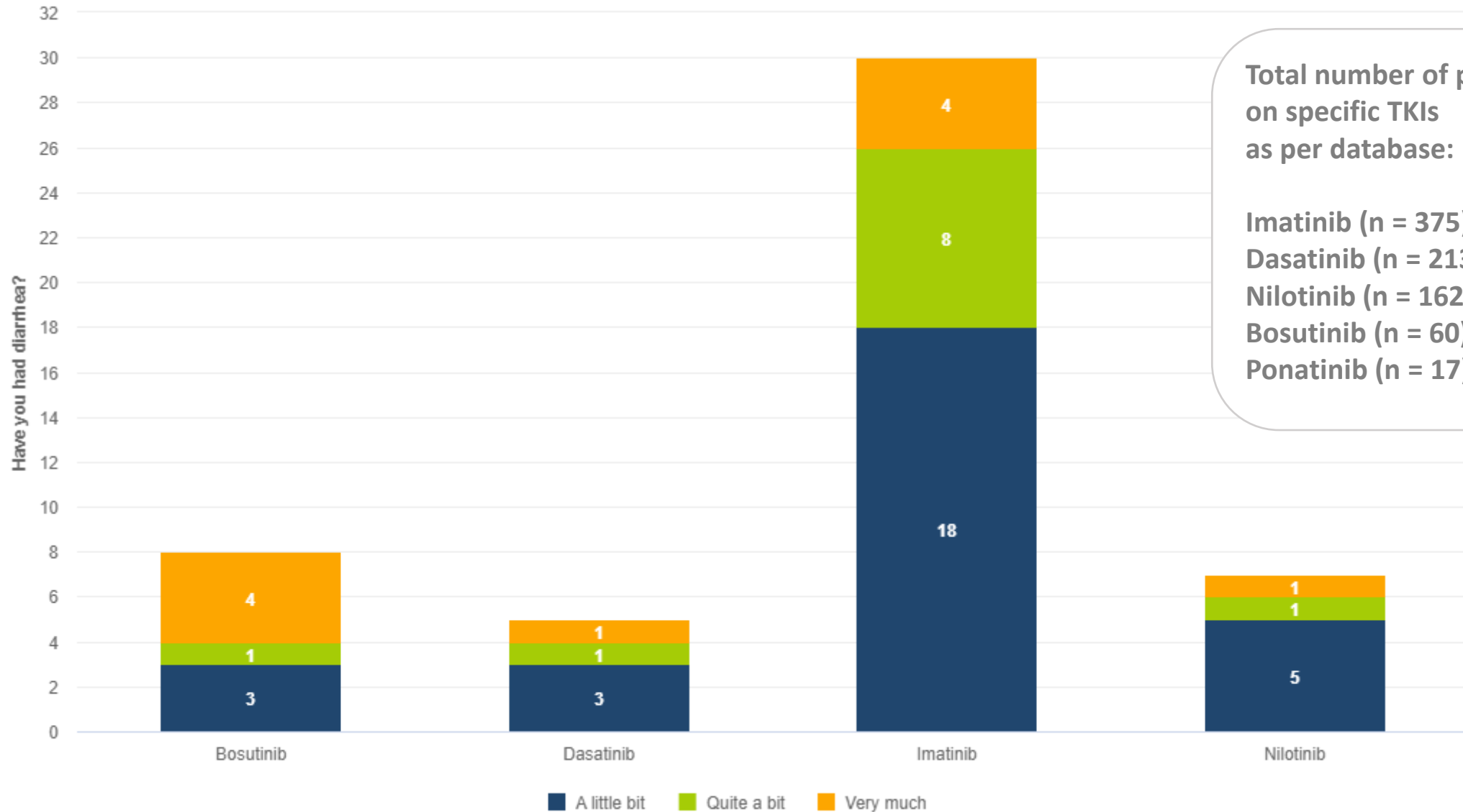




Have you had skin problems (e.g. color changes, itchy, dry or flaking skin)?



Have you had diarrhea?

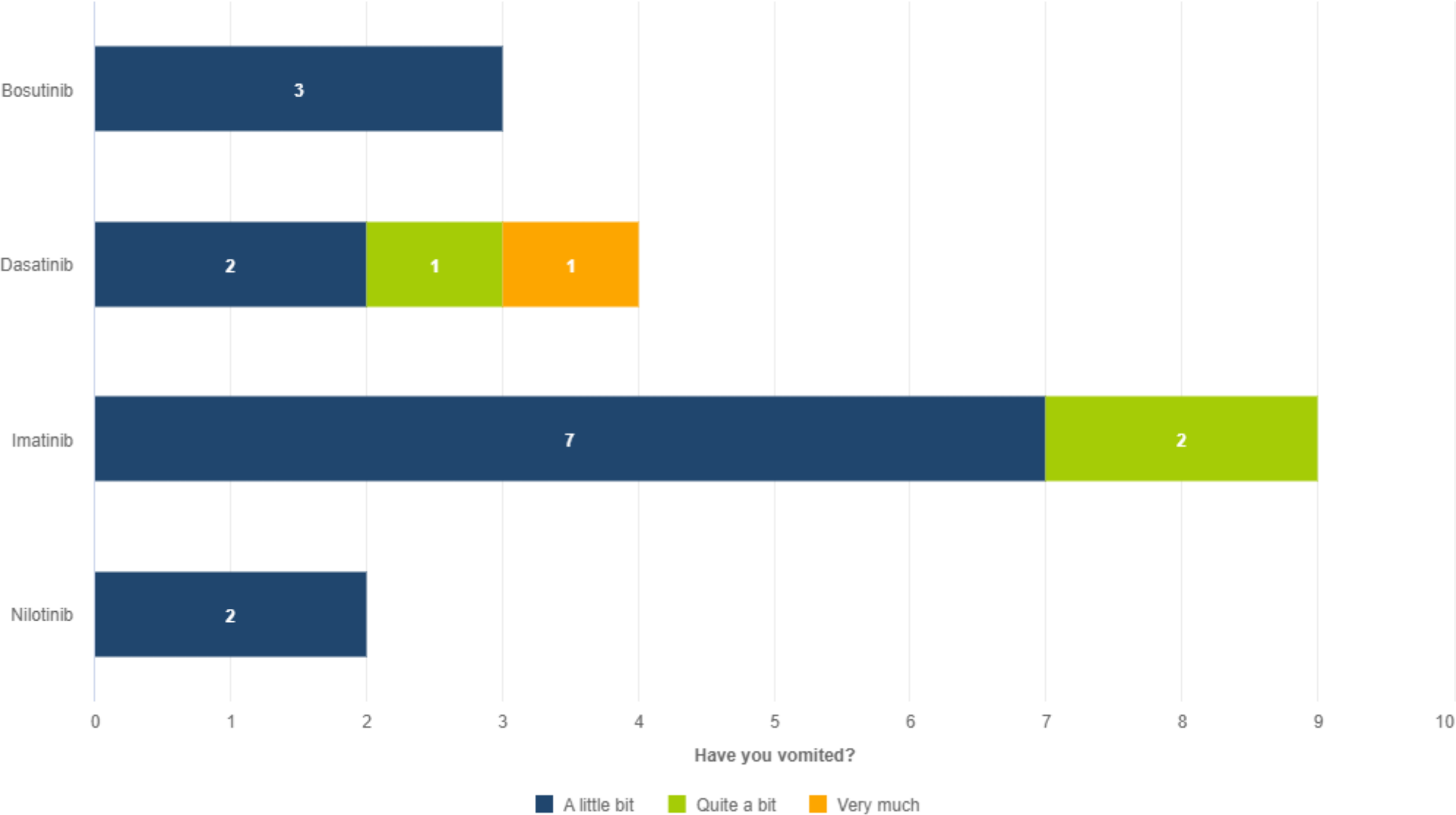


Total number of patients on specific TKIs as per database:

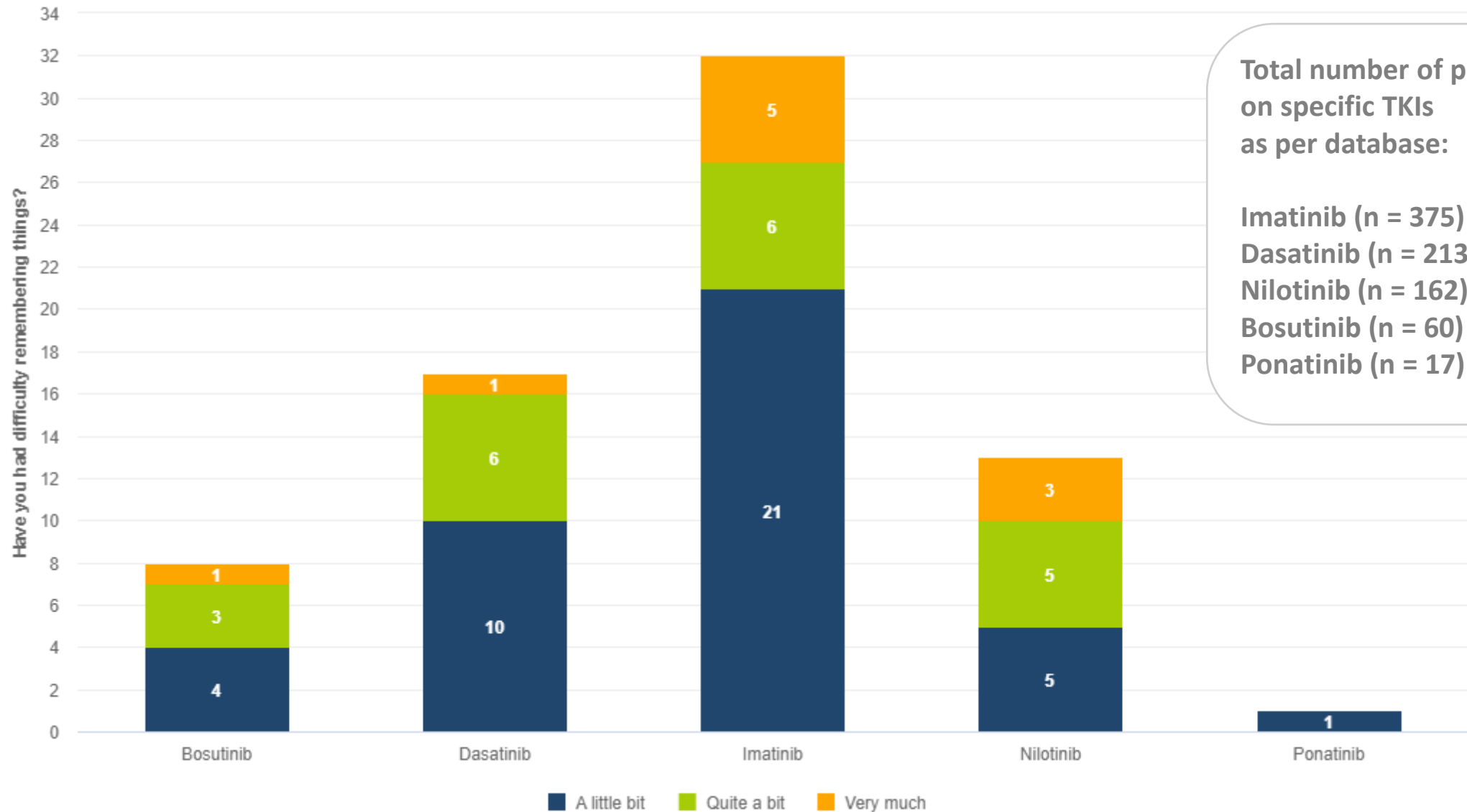
Imatinib (n = 375)
Dasatinib (n = 213)
Nilotinib (n = 162)
Bosutinib (n = 60)
Ponatinib (n = 17)



Have you vomited?



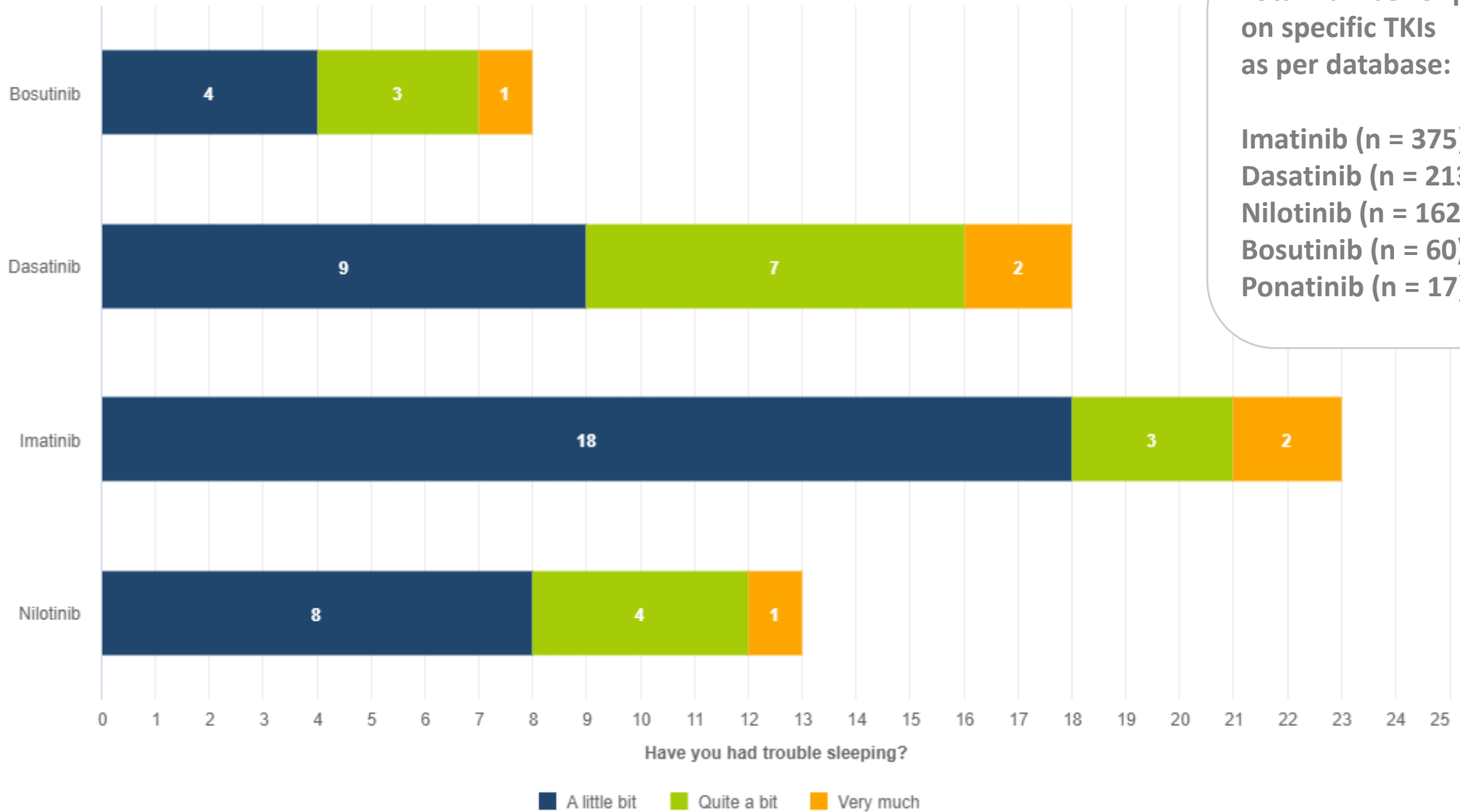
Have you had difficulty remembering things?



Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

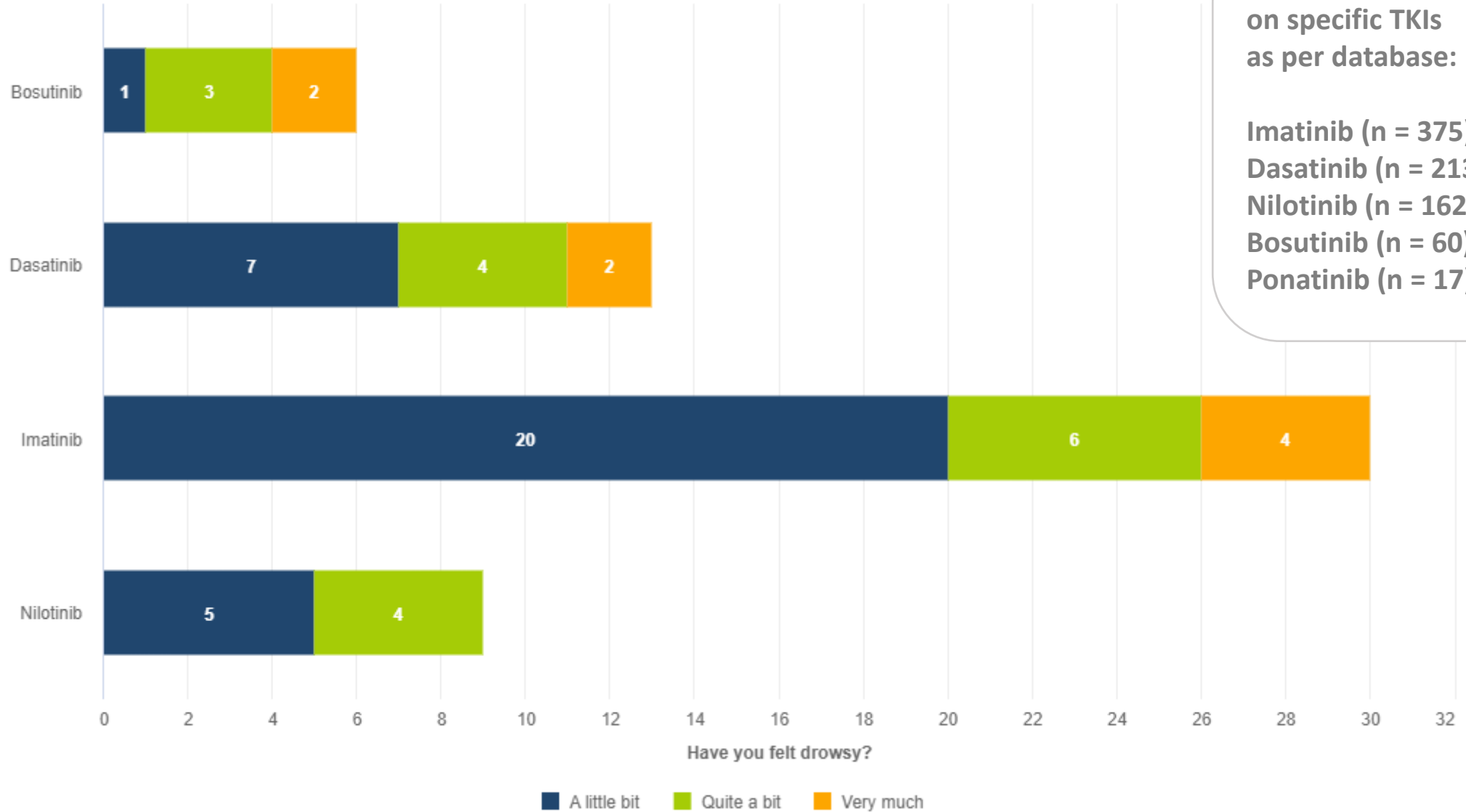
Have you had trouble sleeping?



Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

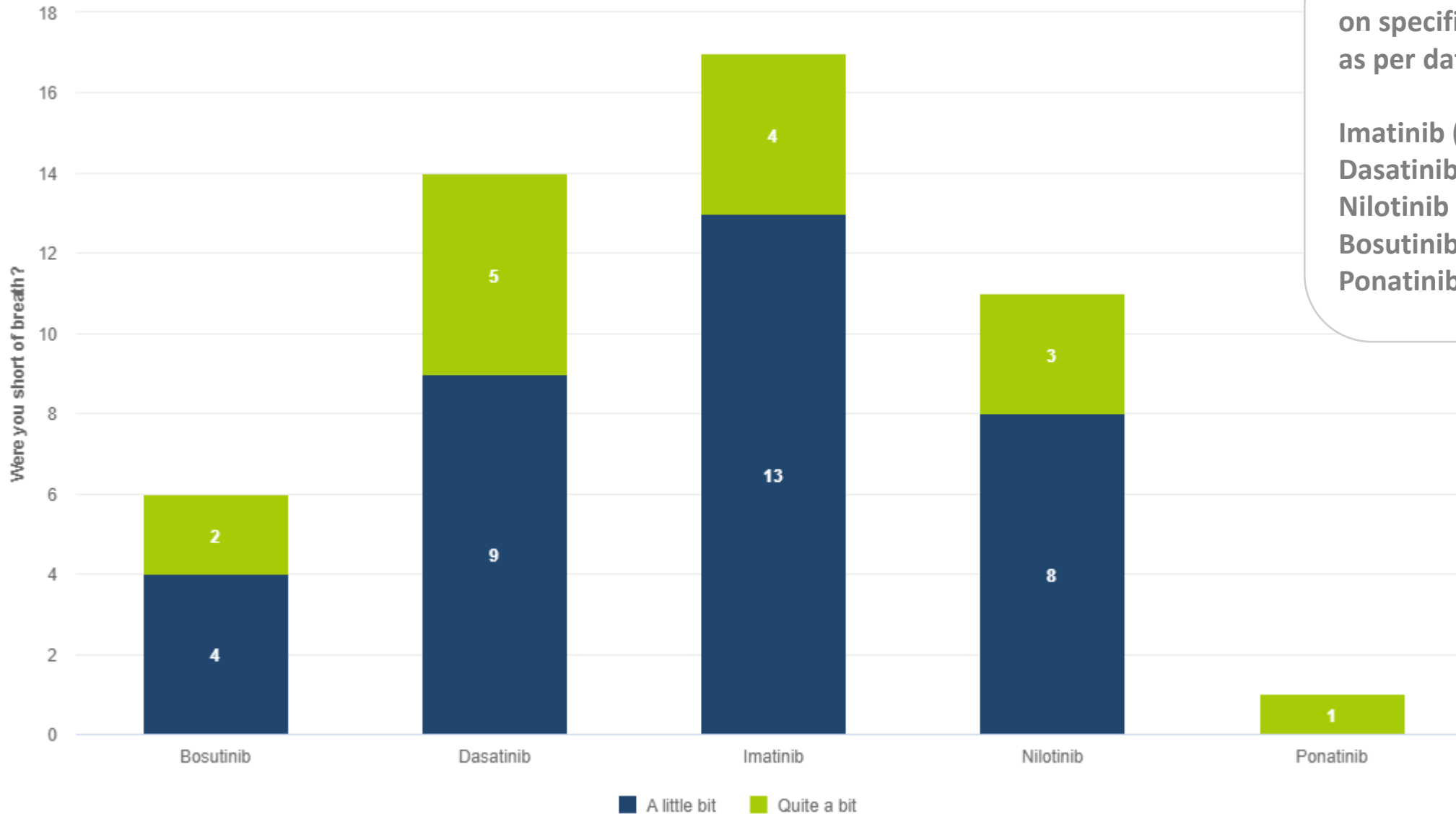
Have you felt drowsy?



Total number of patients on specific TKIs as per database:

- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

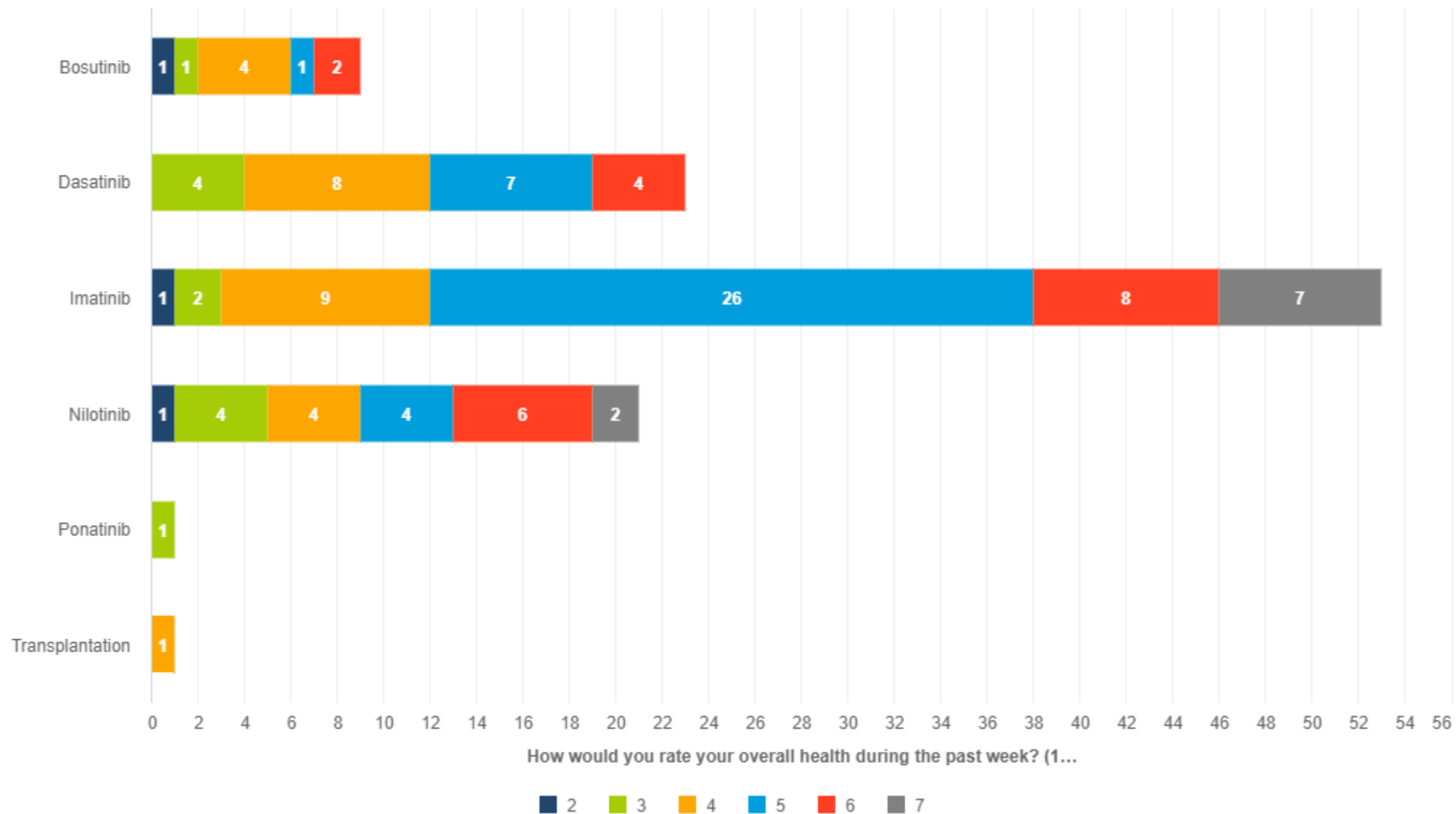
Were you short of breath?



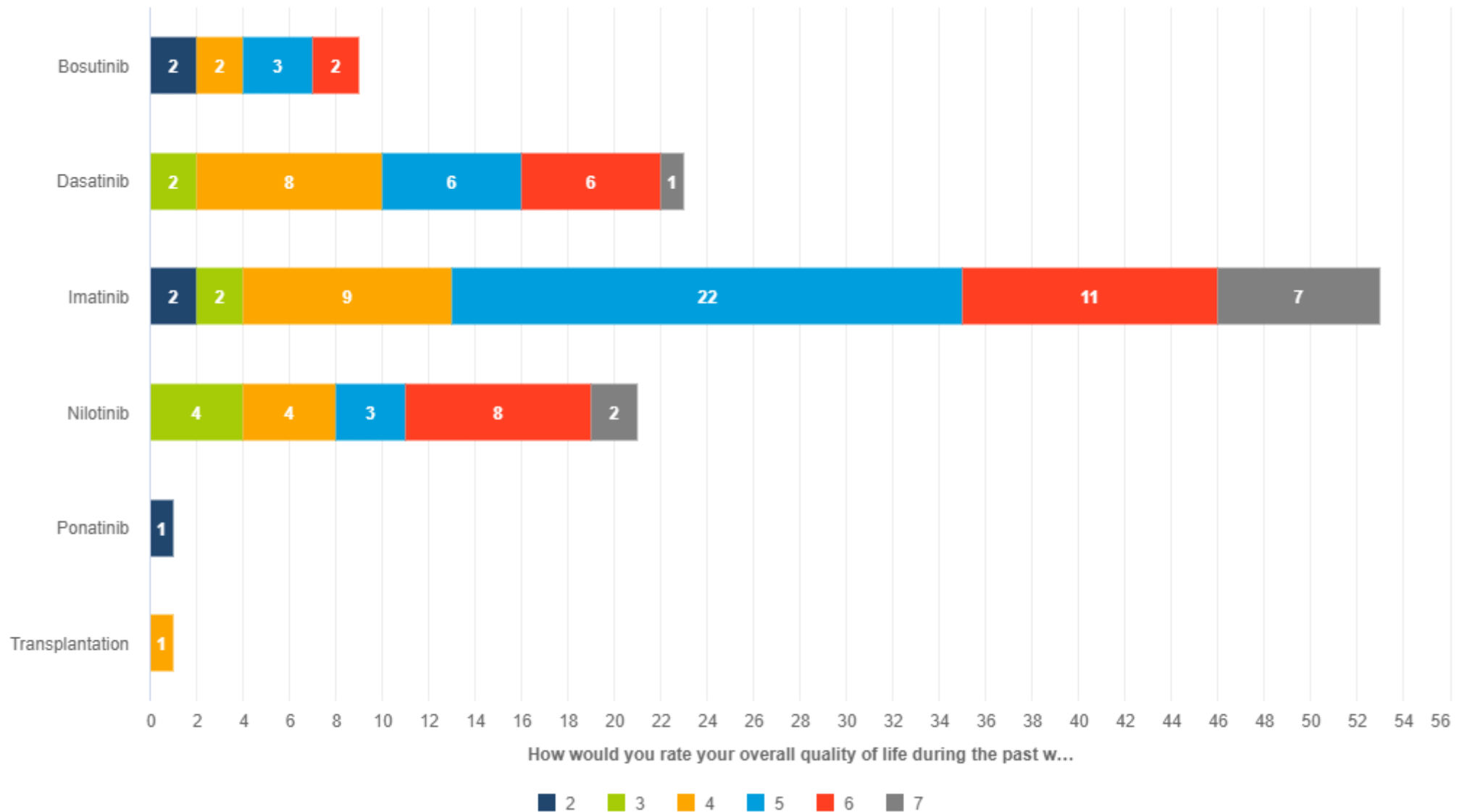
Total number of patients on specific TKIs as per database:

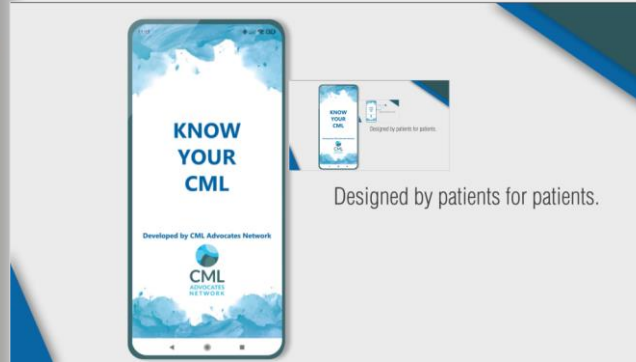
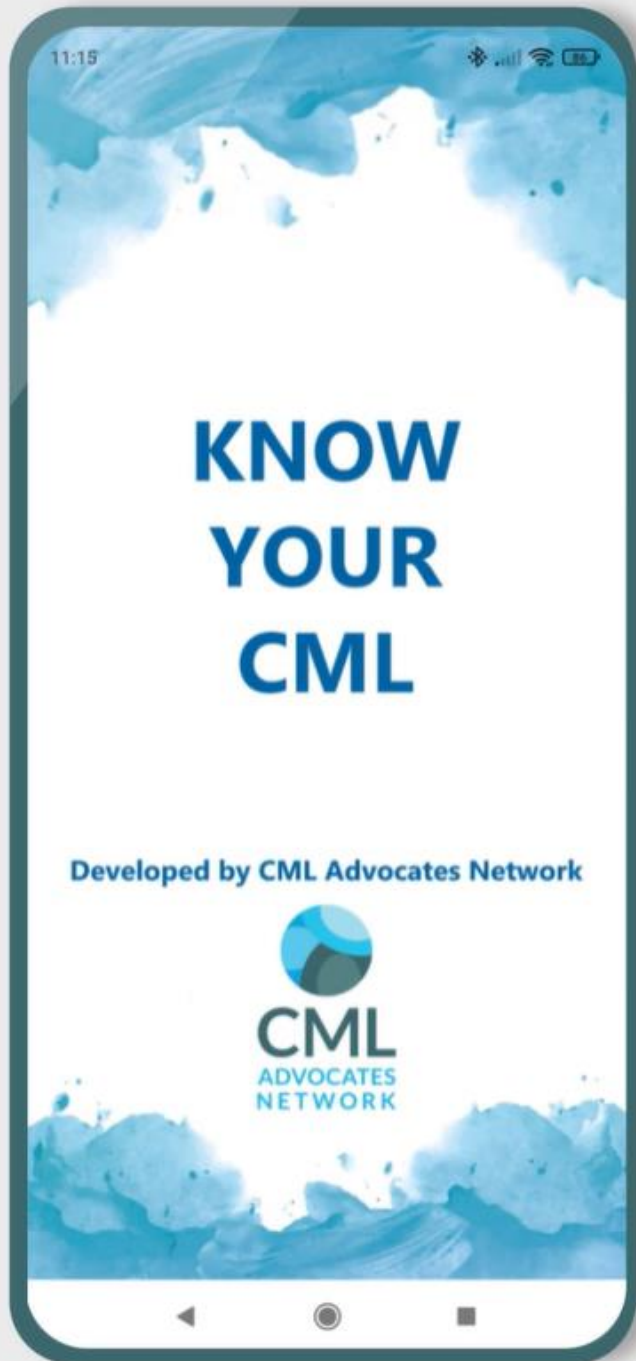
- Imatinib (n = 375)
- Dasatinib (n = 213)
- Nilotinib (n = 162)
- Bosutinib (n = 60)
- Ponatinib (n = 17)

How would you rate your overall health during the past week? (1 = very poor, 7 = excellent)



How would you rate your overall quality of life during the past week? (1 = very poor, 7 = excellent)





Designed by patients for patients.

Designed by patients for patients.