

Real-world  
evidence from  
online patient  
forums can  
complement  
current medical  
perspectives

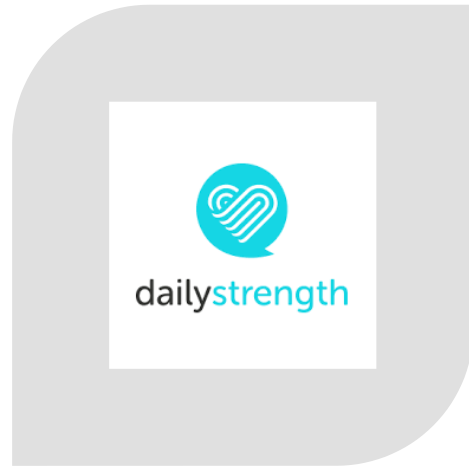
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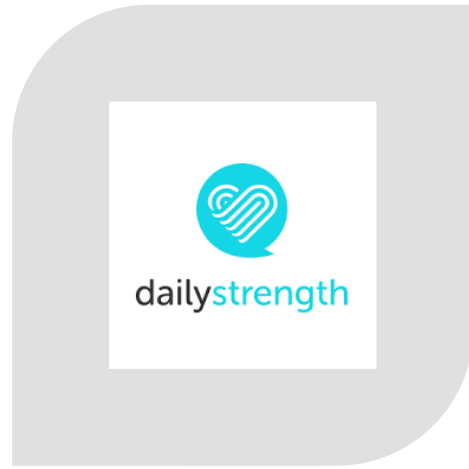


**SIDN**fonds





What are patient forums?



Why patient forums?

# Post-market drug monitoring



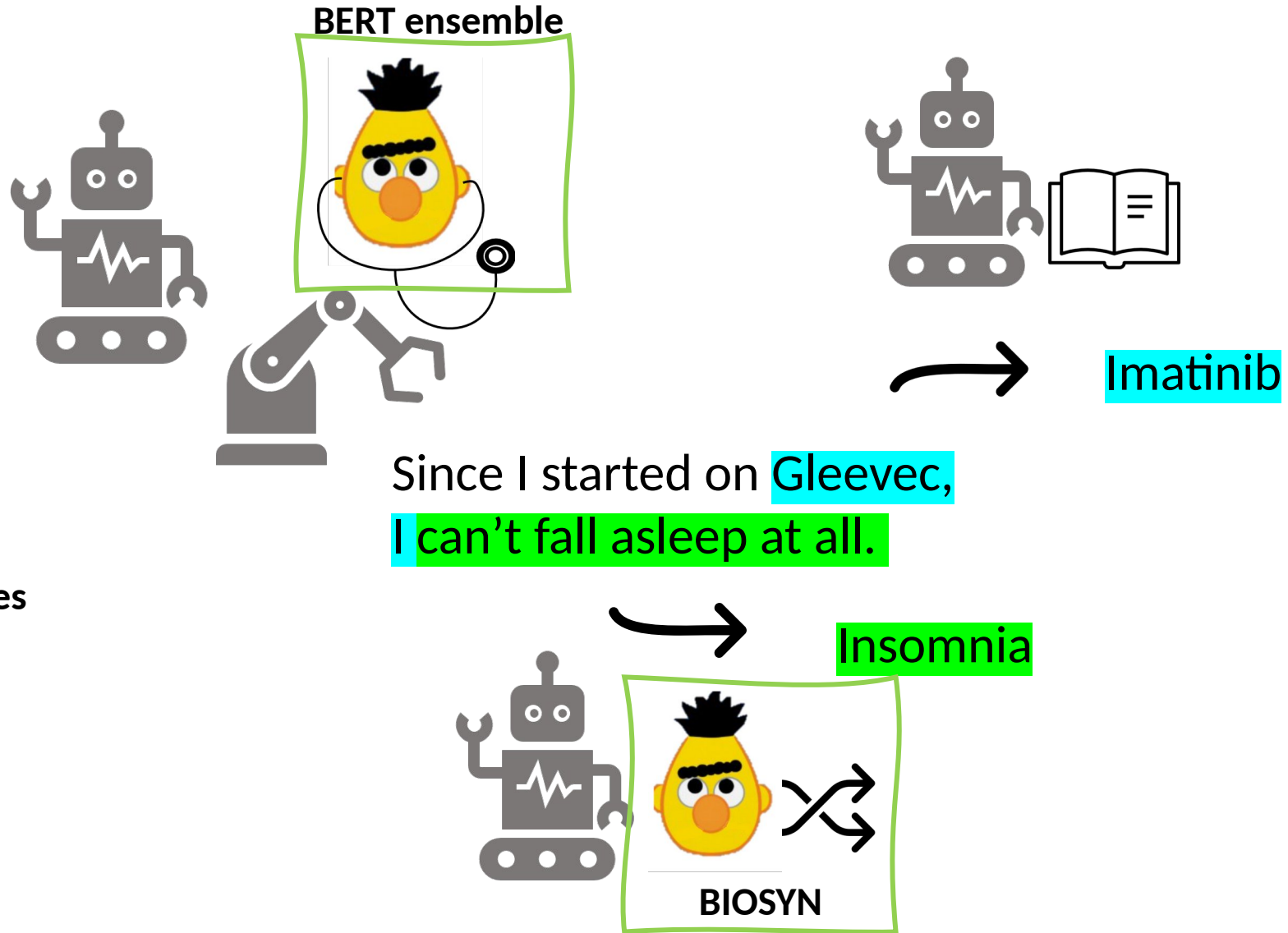
Suffers from under-reporting



Real world evidence from  
patients is necessary



Can be found on patient forum  
discussions

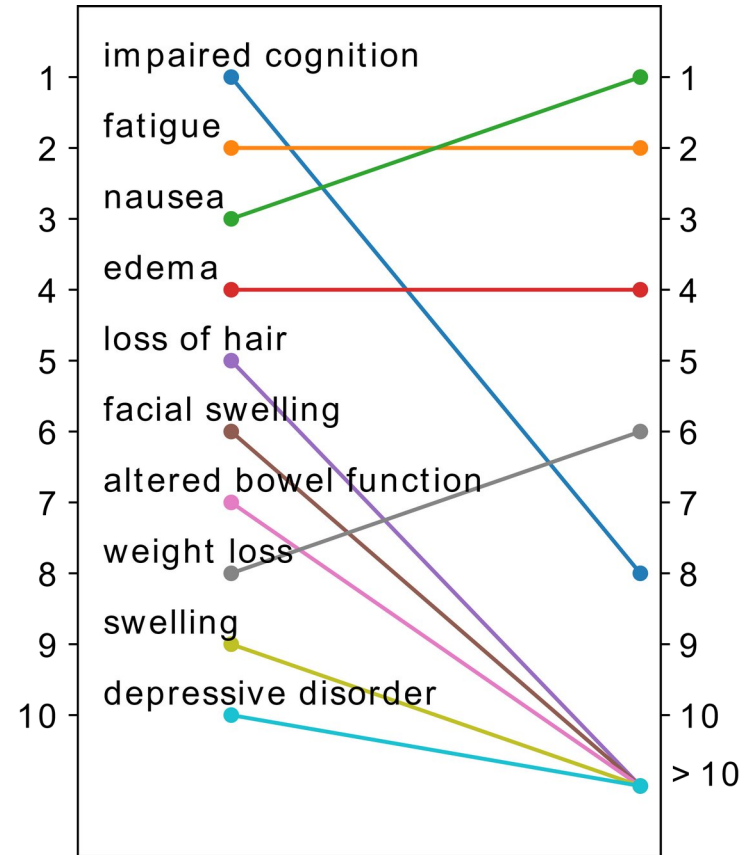


Treatment type	Drug	# of ADE found	# of ADE types
First-line	Imatinib	13,376	685
Second-line	Sunitinib	2,335	324
Third-line	Regorafenib	319	226
Fourth-line	Ripretinib	319	90
PDGFRA exon 18 mutations	Avapritinib	297	112
Off-label	Nilotinib	59	40
Off-label	Pazopanib	51	27
Off-label	Sorafenib	47	32
Off-label	Ponatinib	17	13
	Unknown	2,948	497
	Total	21,051	1,086

Side effects on forum

Rank on forum

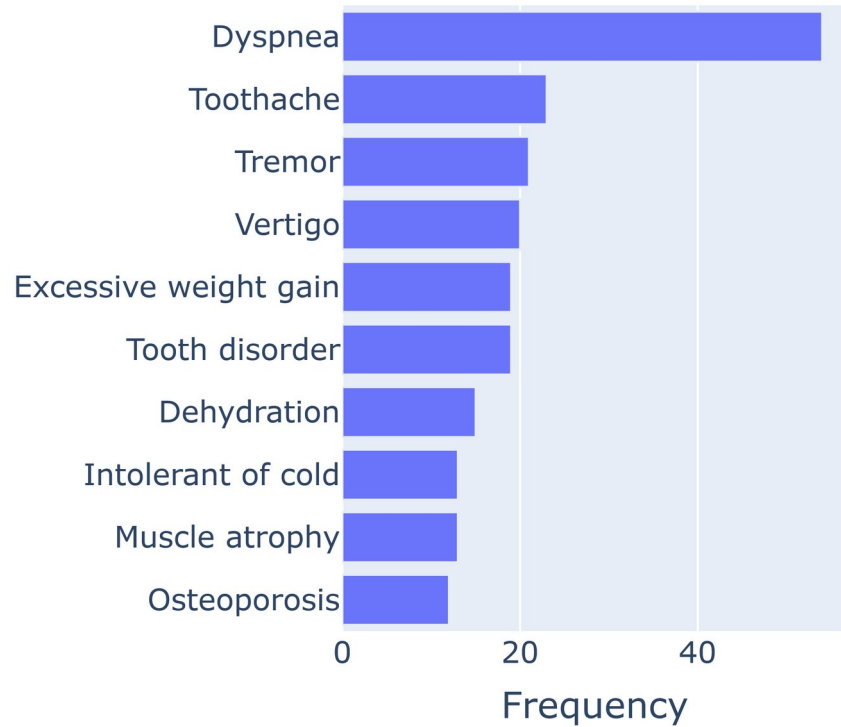
Rank in clinical trial



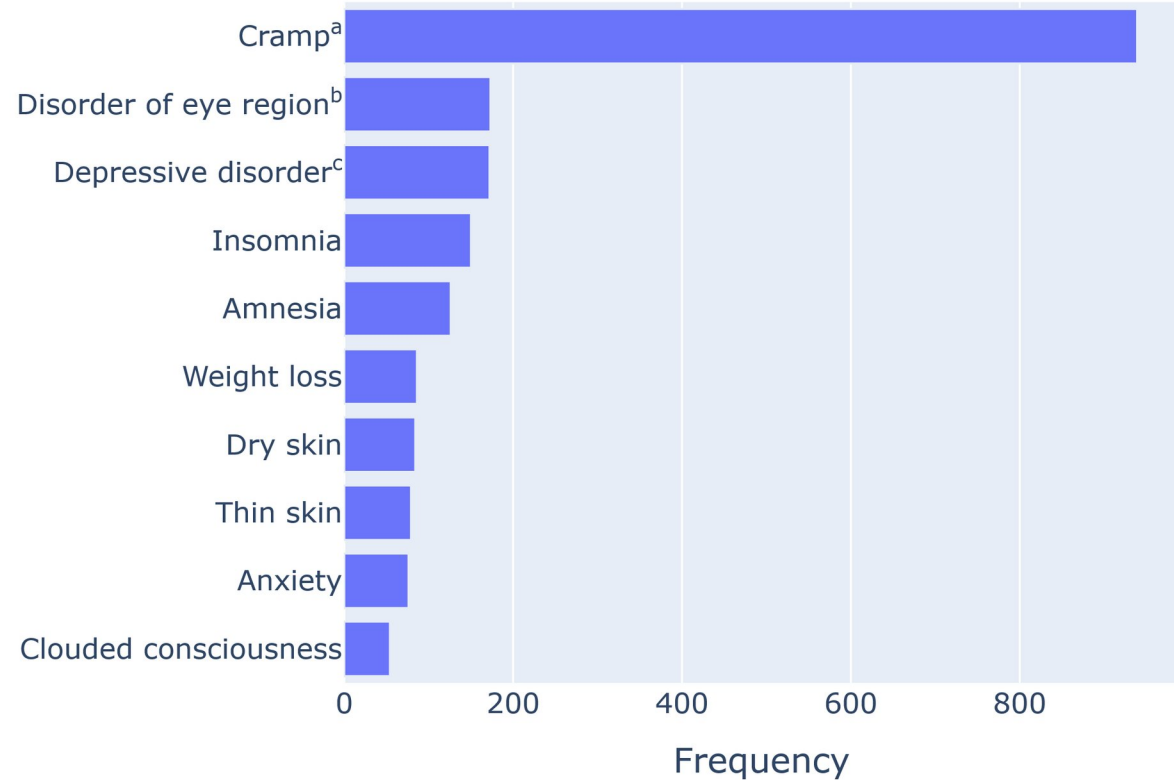
Top 10 for new medicine  
avapritinib



Top 10 long-term side effects



Top 10 novel side effects



<sup>a</sup>includes Cramp in limb, Cramp in lower leg and Cramp in foot

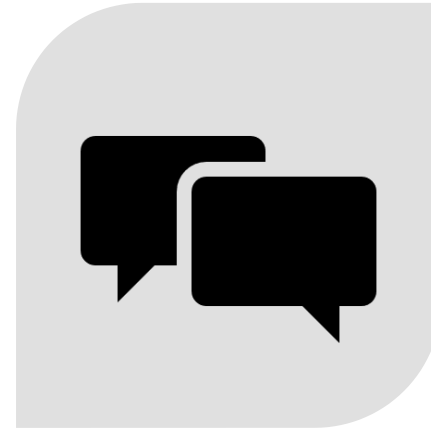
<sup>b</sup>includes Contusion of eye, Red eye, Disorder of eye and Dry eyes

<sup>c</sup>includes Major depressive disorder, Mild depression and Depressed mood

# Side effects for established imatinib

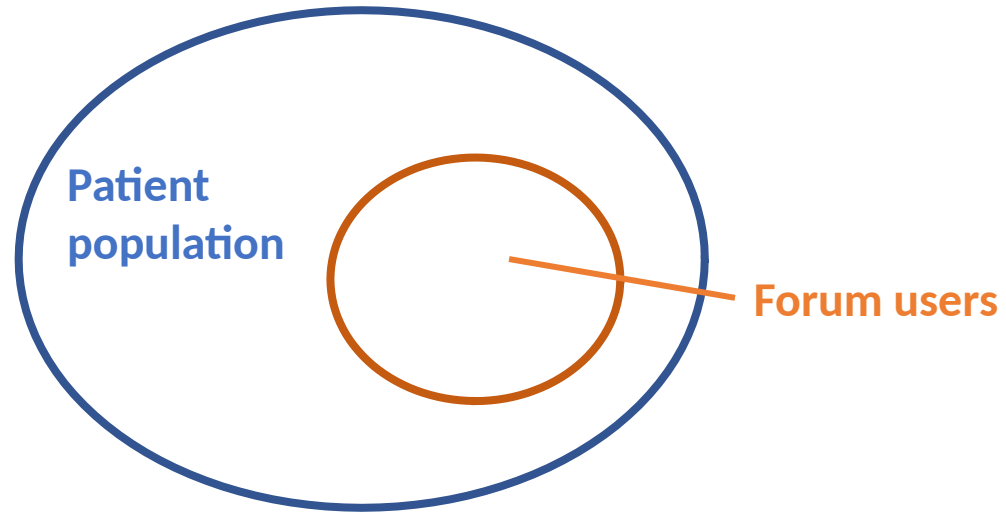


VS



# Comparison with survey data

Den Hollander, D, Dirkson, A., Verberne, S., Kraaij W., van Oortmerssen, G., Gelderblom, A.J., Oosten, A., Reyners, A.K.L, Steeghs, N., van der Graaf, W., Desar, I. & Husson, O. Measuring patient-reported symptoms of imatinib through questionnaires and a forum for patients with GIST: how do they complement each other? Under review at Cancer Medicine



Sample bias of forum users



# Coping with side effects



No systematic collection



Patients gain an overview

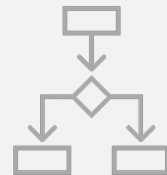


Doctors can figure out why it works & if it is safe

# Stay tuned for



First pipeline for coping  
strategy extraction



Sample bias of forum data



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