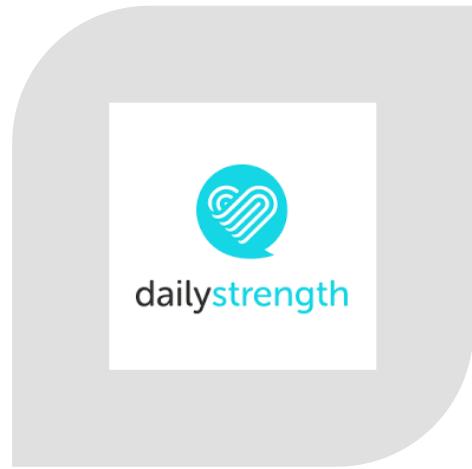


Real-world
evidence from
online patient
forums can
complement
current medical
perspectives

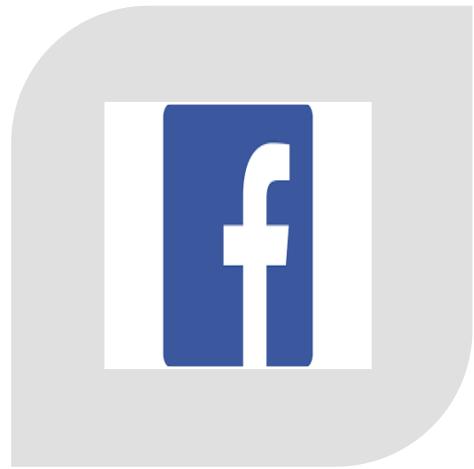
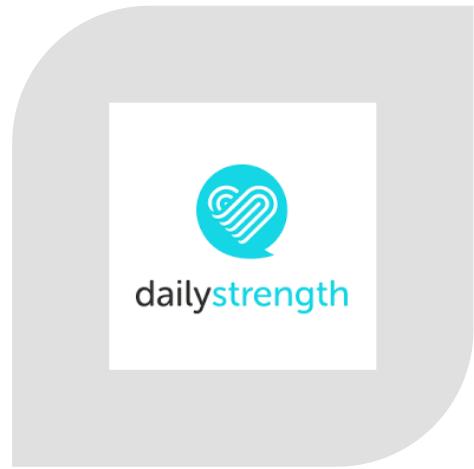




SIDN fonds

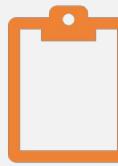


What are patient forums?



Why patient forums?

Post-market drug monitoring



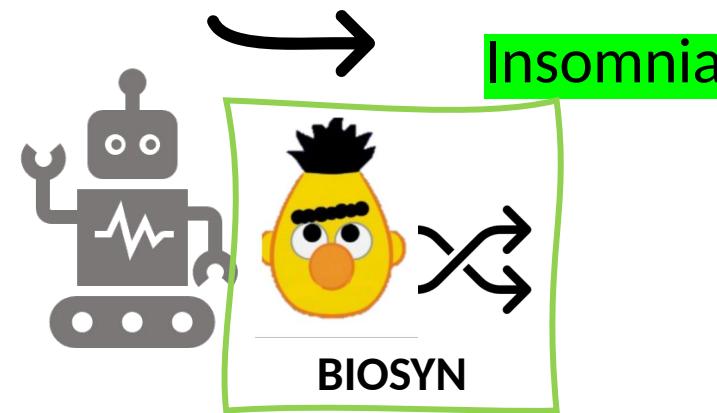
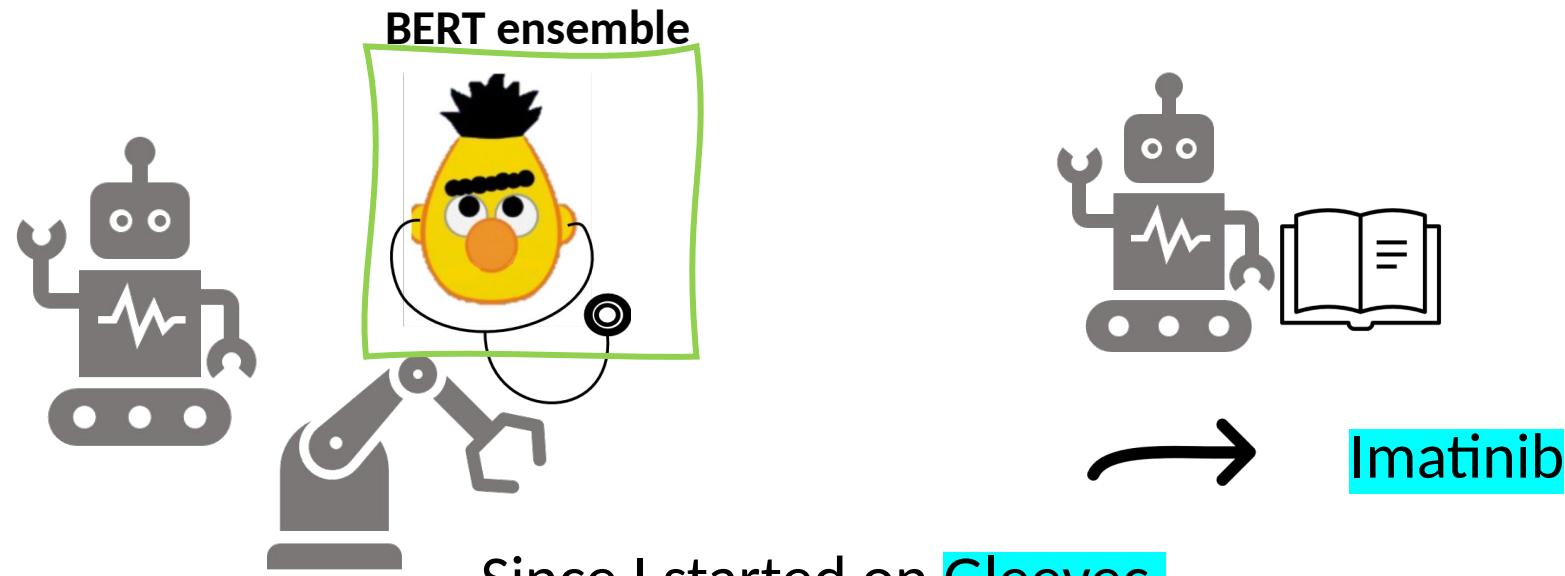
Suffers from under-reporting



Real world evidence from
patients is necessary



Can be found on patient forum
discussions

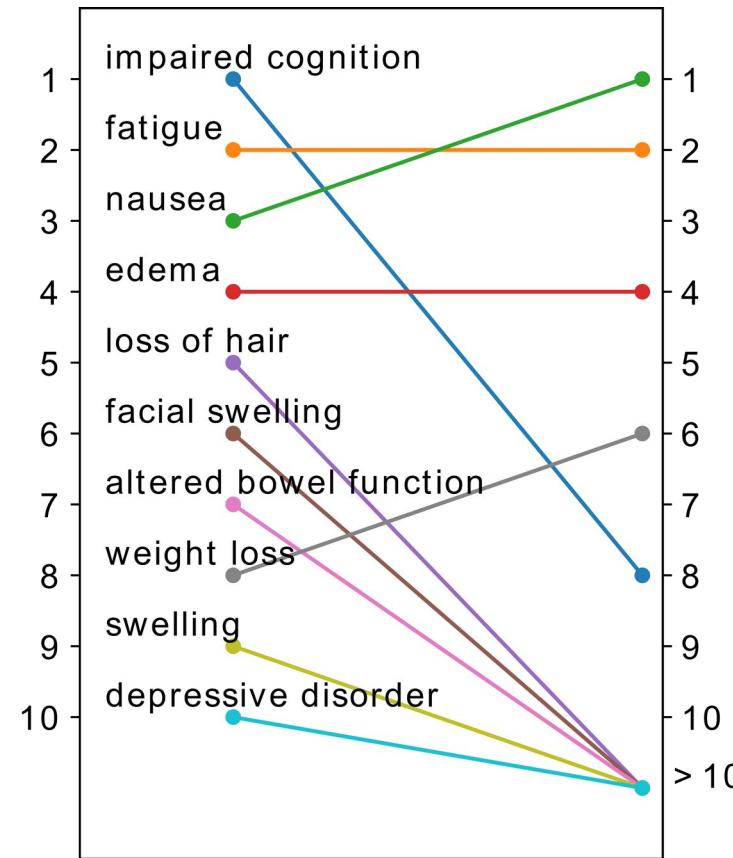


Treatment type	Drug	# of ADE found	# of ADE types
First-line	Imatinib	13,376	685
Second-line	Sunitinib	2,335	324
Third-line	Regorafenib	319	226
Fourth-line	Ripretinib	319	90
PDGFRA exon 18 mutations	Avapritinib	297	112
Off-label	Nilotinib	59	40
Off-label	Pazopanib	51	27
Off-label	Sorafenib	47	32
Off-label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

Side effects on forum

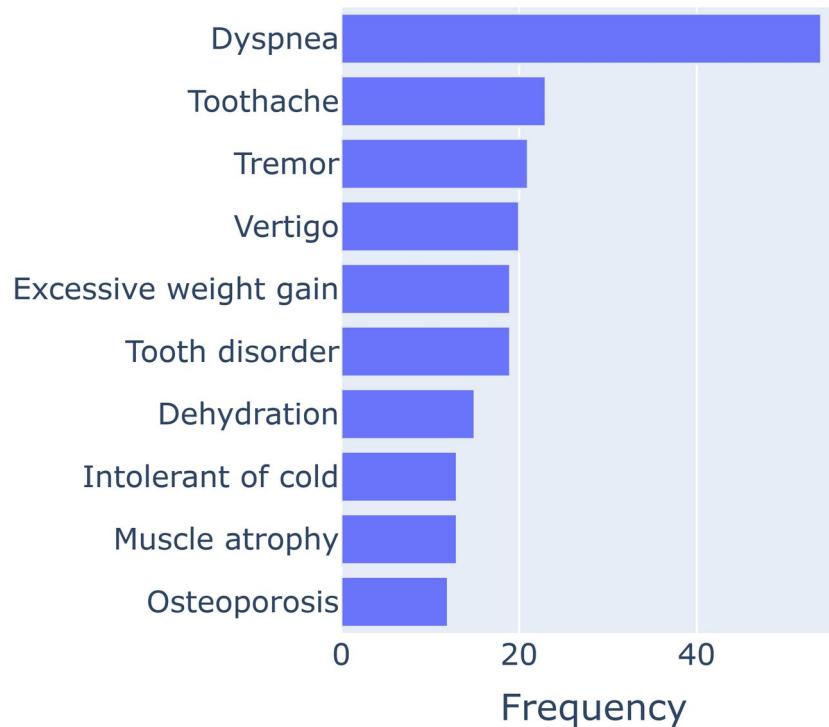
Rank on forum

Rank in clinical trial

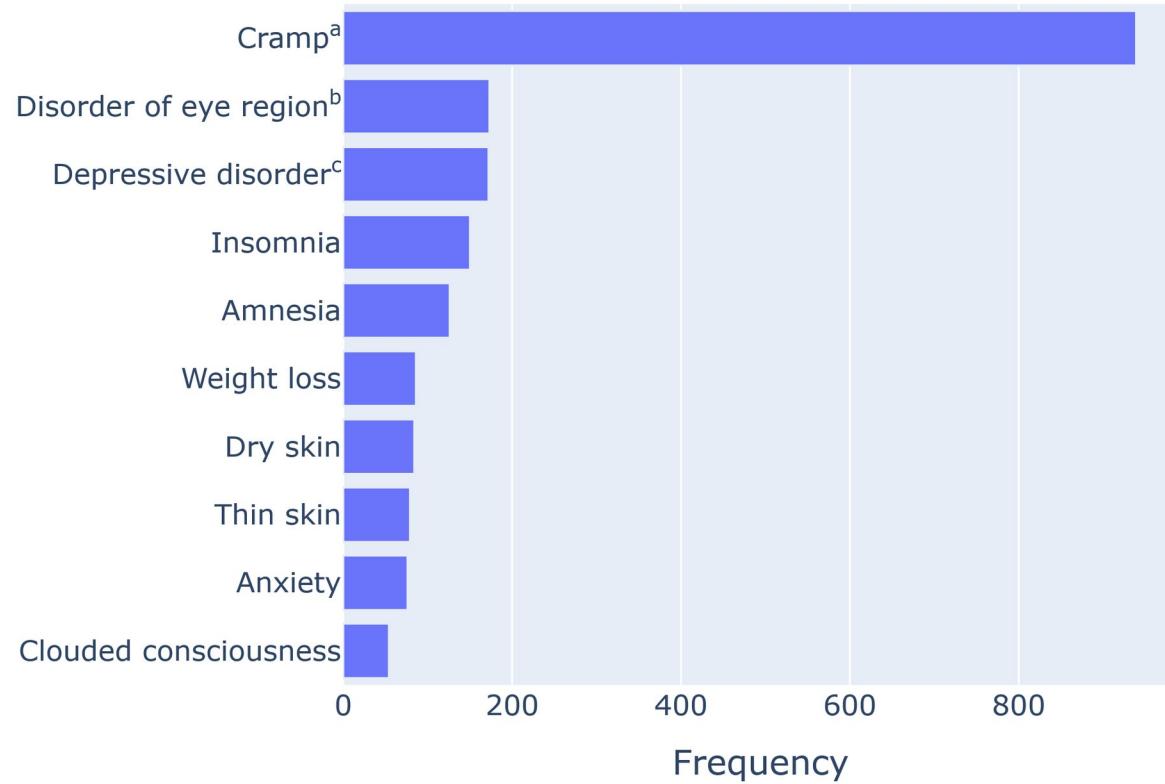


Top 10 for new medicine
avapritinib

Top 10 long-term side effects



Top 10 novel side effects



^aincludes Cramp in limb, Cramp in lower leg and Cramp in foot

^bincludes Contusion of eye, Red eye, Disorder of eye and Dry eyes

^cincludes Major depressive disorder, Mild depression and Depressed mood

Side effects for established imatinib

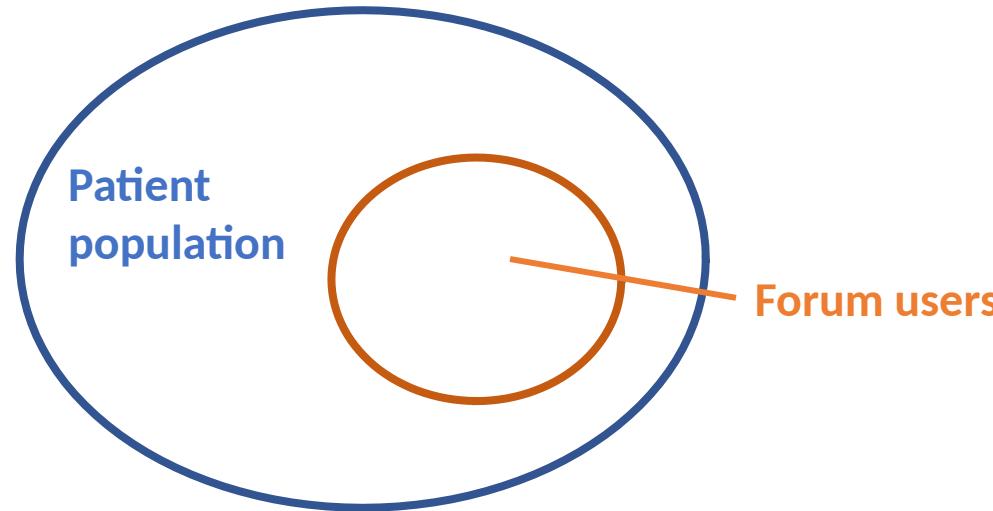


VS



Comparison with survey data

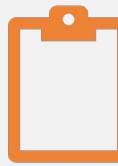
Den Hollander, D, Dirkson, A., Verberne, S., Kraaij W., van Oortmerssen, G., Gelderblom, A.J., Oosten, A., Reyners, A.K.L, Steeghs, N., van der Graaf, W., Desar, I. & Husson, O. Measuring patient-reported symptoms of imatinib through questionnaires and a forum for patients with GIST: how do they complement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



Sample bias of forum users



Coping with side effects



No systematic collection



Patients gain an overview

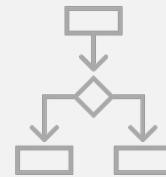


Doctors can figure out why it works & if it is safe

Stay tuned
for



First pipeline for coping
strategy extraction



Sample bias of forum data



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