

Patient discussion
forums as data source
for adverse drug
reactions



SIDNfunds

Post-market drug monitoring



Suffers from under-reporting



Real world evidence from
patients necessary

Patient experiences of side effects

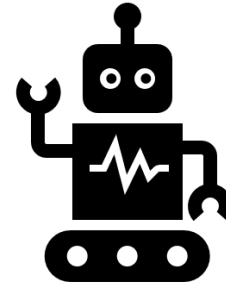
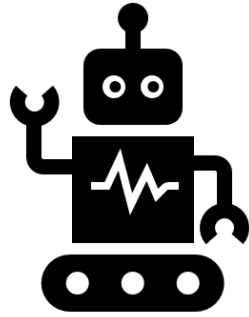
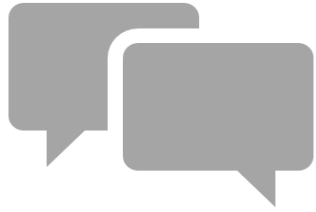


Can be asked



Can also be found on patient
forum discussions

Forum for
GIST patients

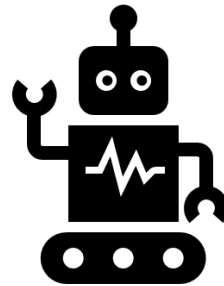


Imatinib

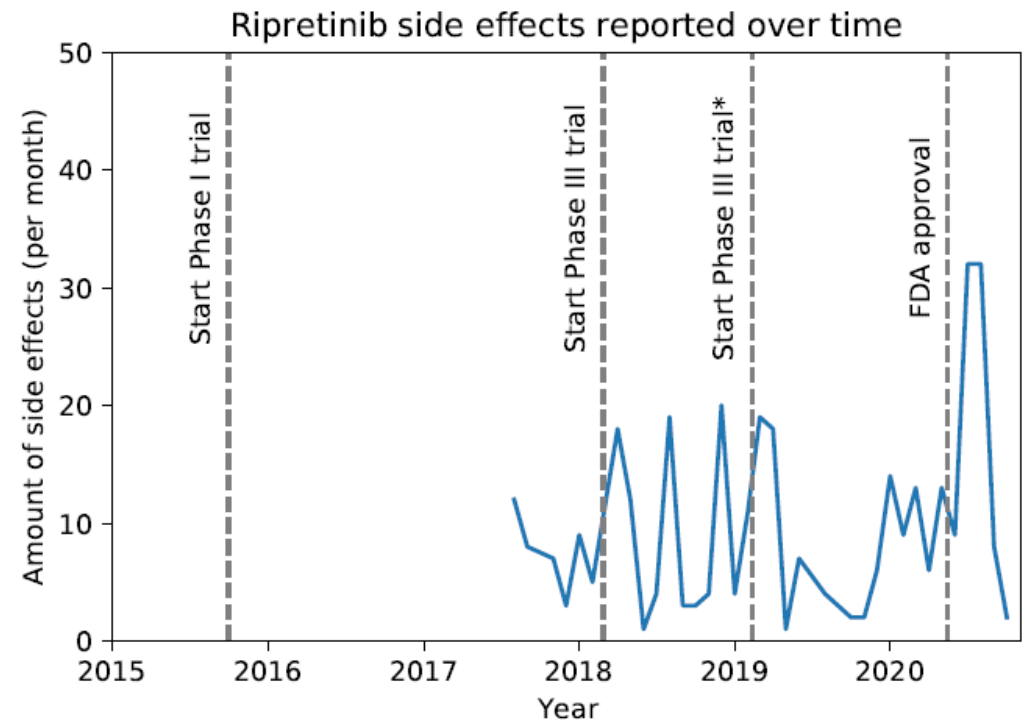
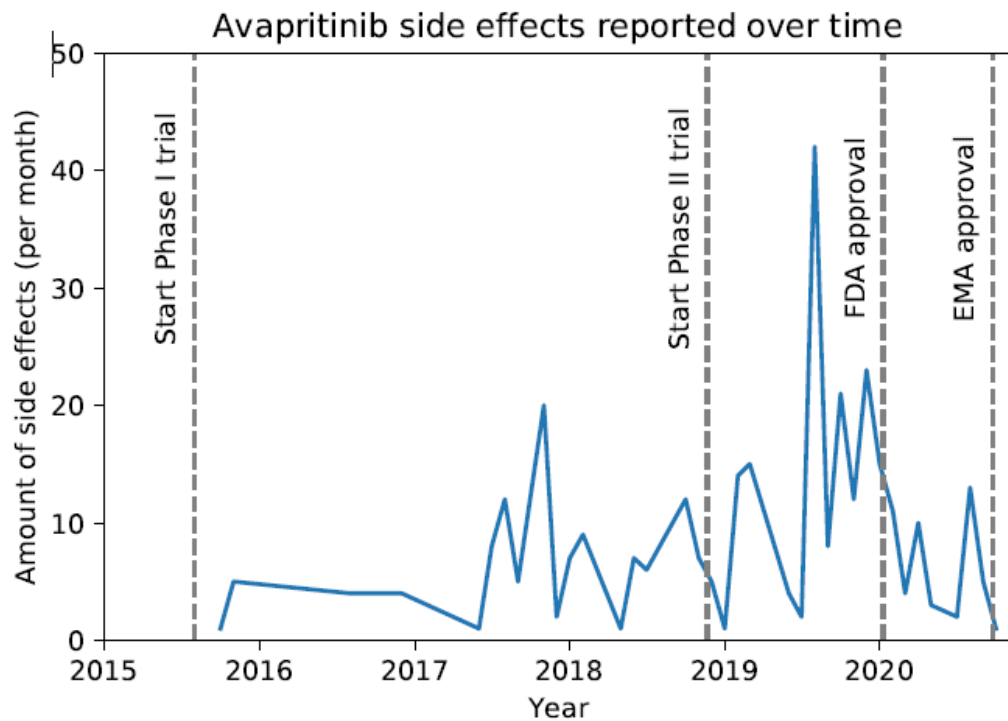
Since I started on **Gleevec**,
I **can't fall asleep** at all.



Insomnia



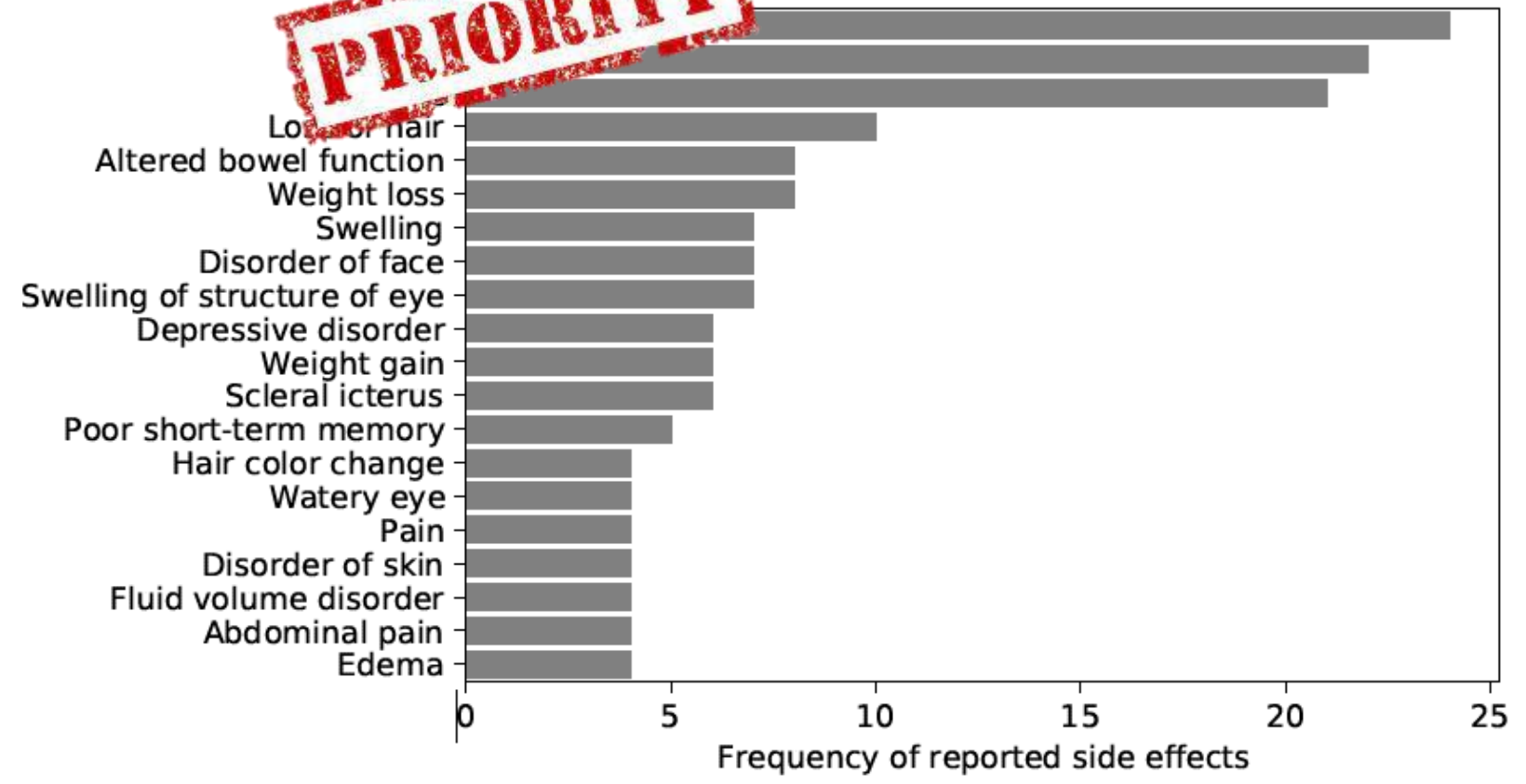
Drugs over time



Which ADR are reported?

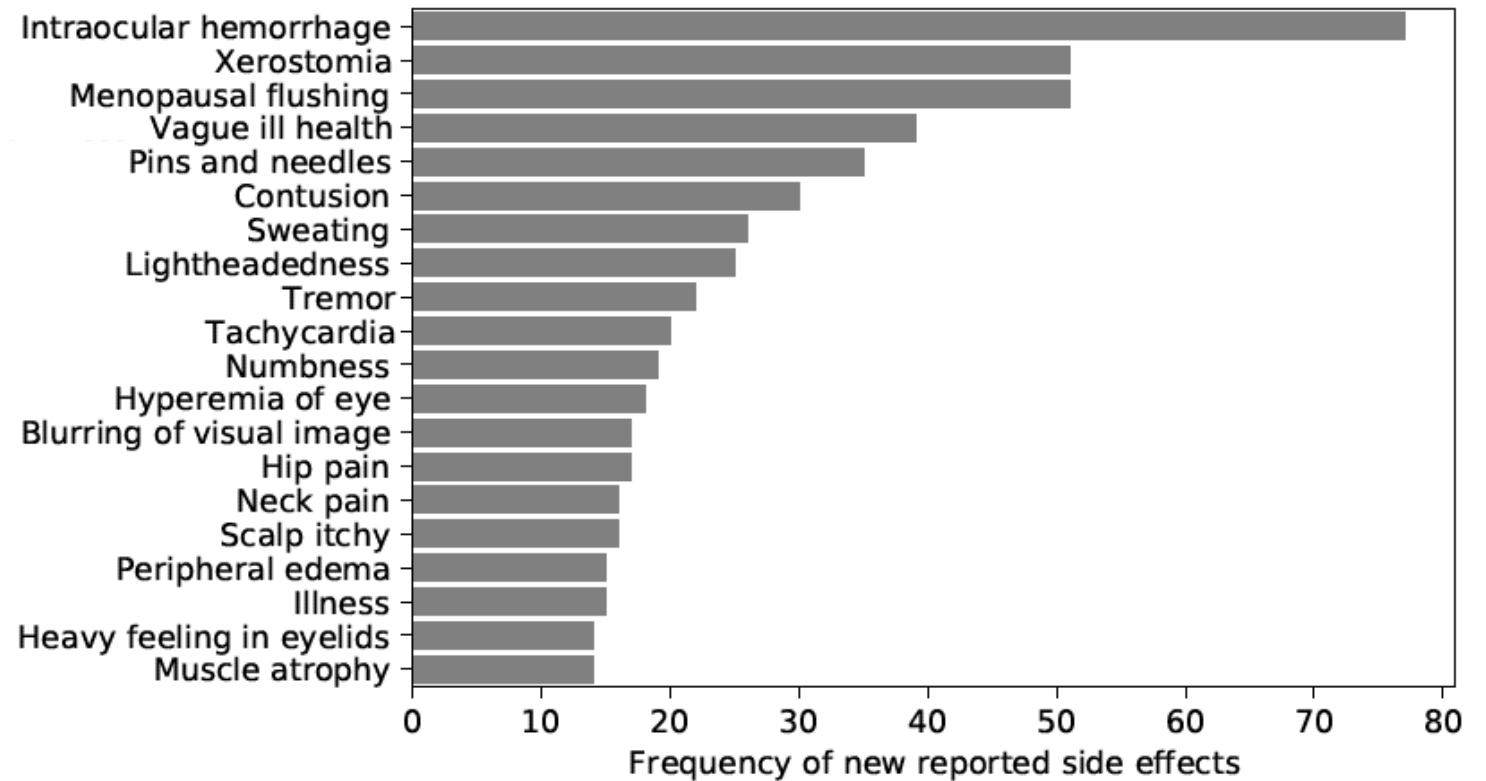
PRIORITY


Top 20 common side effects reported for avapritinib



Long term side effects

The 20 most common new side effects for imatinib after 5 years





Compared to
registration
trials

What is next?



Advice on how to cope with side effects



Comparison with survey data on ADR



How representative is a forum?