



GIST/PRIME

Patient Registry Department



The Life Raft
GROUP 

GIST/PRIME PATIENT REGISTRY



- The largest GIST registry in the world with over 1 900 patients from more than 67 countries.
- Ongoing research study where GIST patients and caregivers volunteer their information regarding GIST.
- Information is used to understand the natural history of GIST, treatment outcomes, and to help accelerate research with our Real World Evidence Data.
- Enhanced by GIST/Prime, the web-based patient-facing front end of our registry.



PATIENT PROFILING

1981

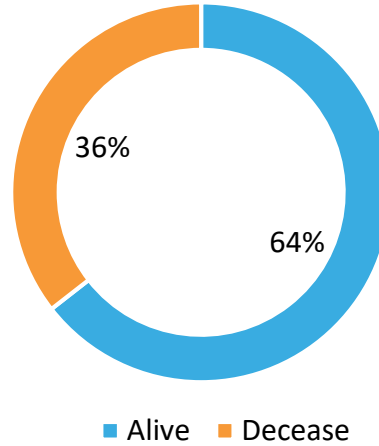
GIST/PRIME MEMBERS

124

NEW GIST/PRIME MEMBERS

400+

GIST/PRIME DATA FIELDS



Median Overall Survival from Diagnosis

12.5 years

Average Age of Diagnosis

51 years

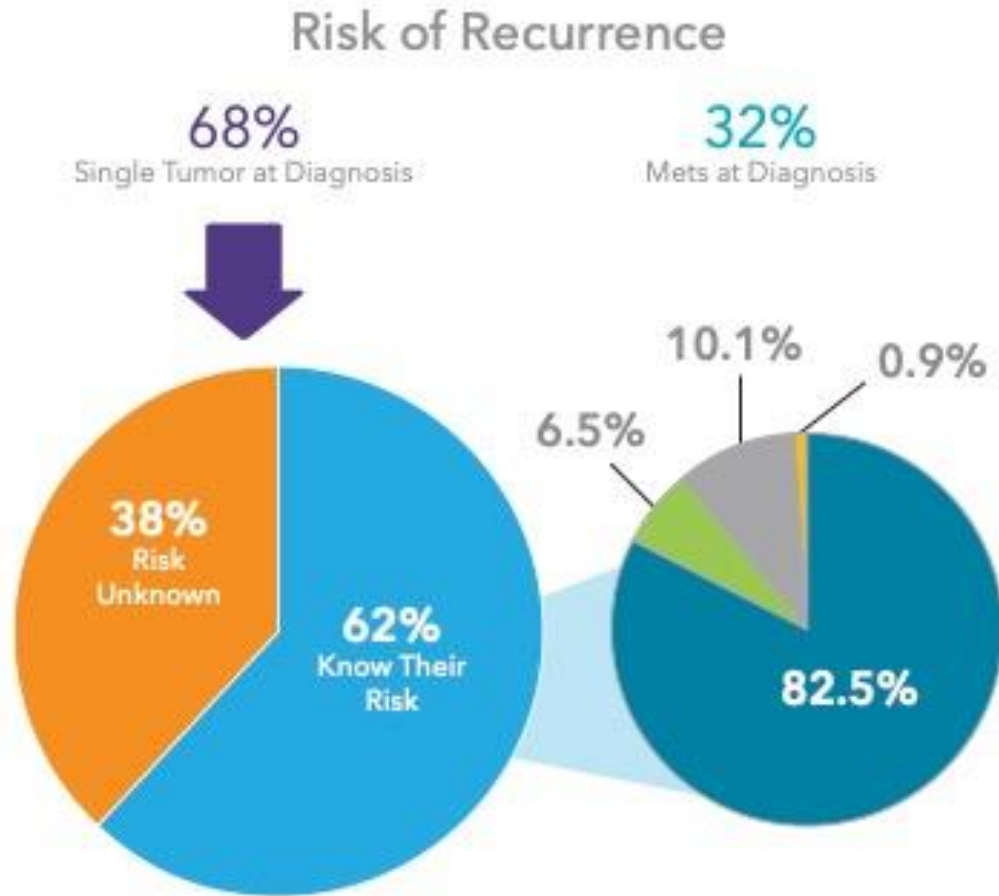
Youngest diagnosed at

5 years old and

the oldest at 98 years old



RISK OF RECURRENCE



There are several different methods used to classify the risk of recurrence in GIST. The Patient Registry uses the Modified NIH Method, which looks at primary tumor size, mitotic count, and location.



MEDICATION

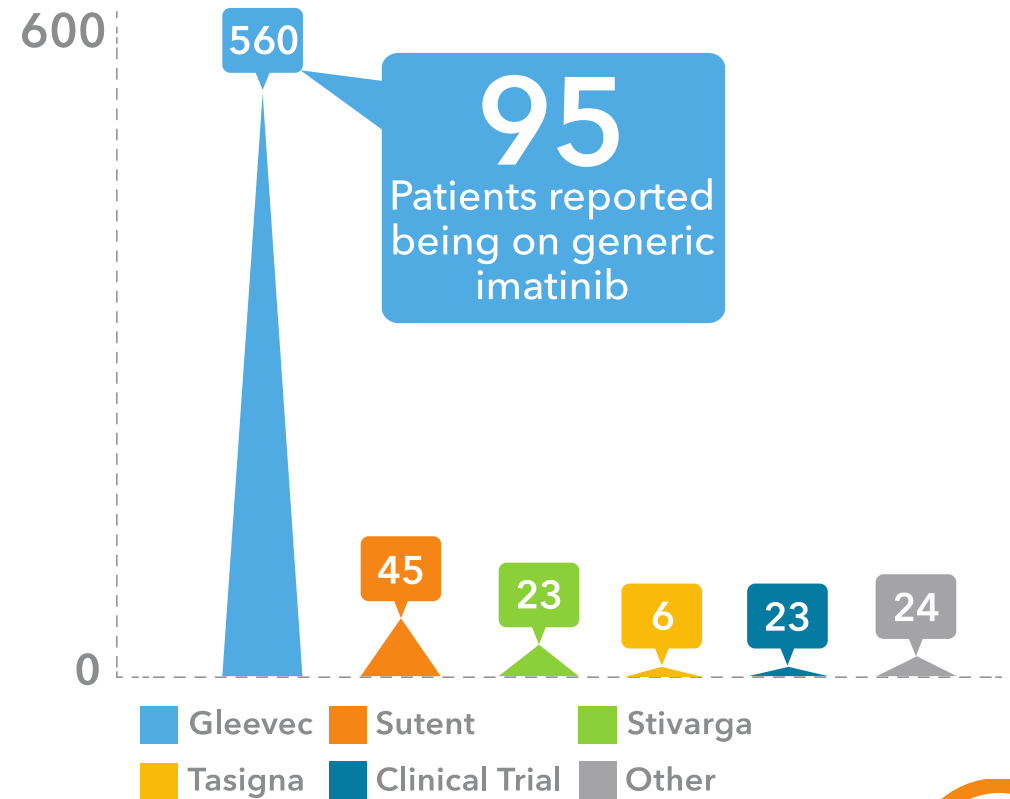
675 Number of living patients on medication:

Generics: **95**



10 patients entered a clinical trial this year

Medication



MUTATIONAL STATUS



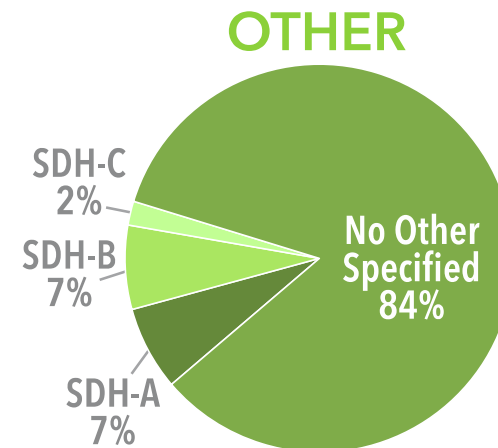
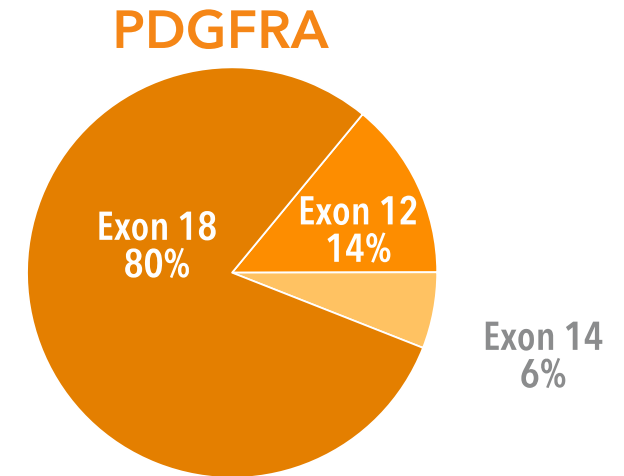
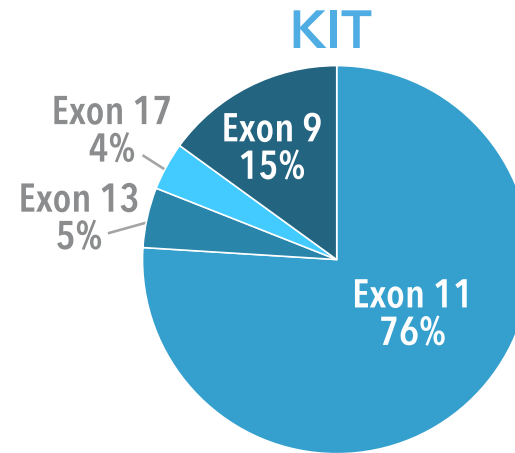
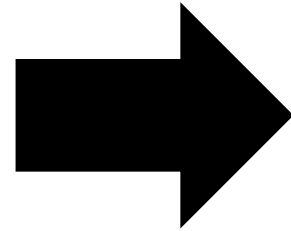
It is estimated that only 15-20% of GIST patients nationwide have mutational testing performed

by contrast **52%** of LRG Patient Registry members know their mutation

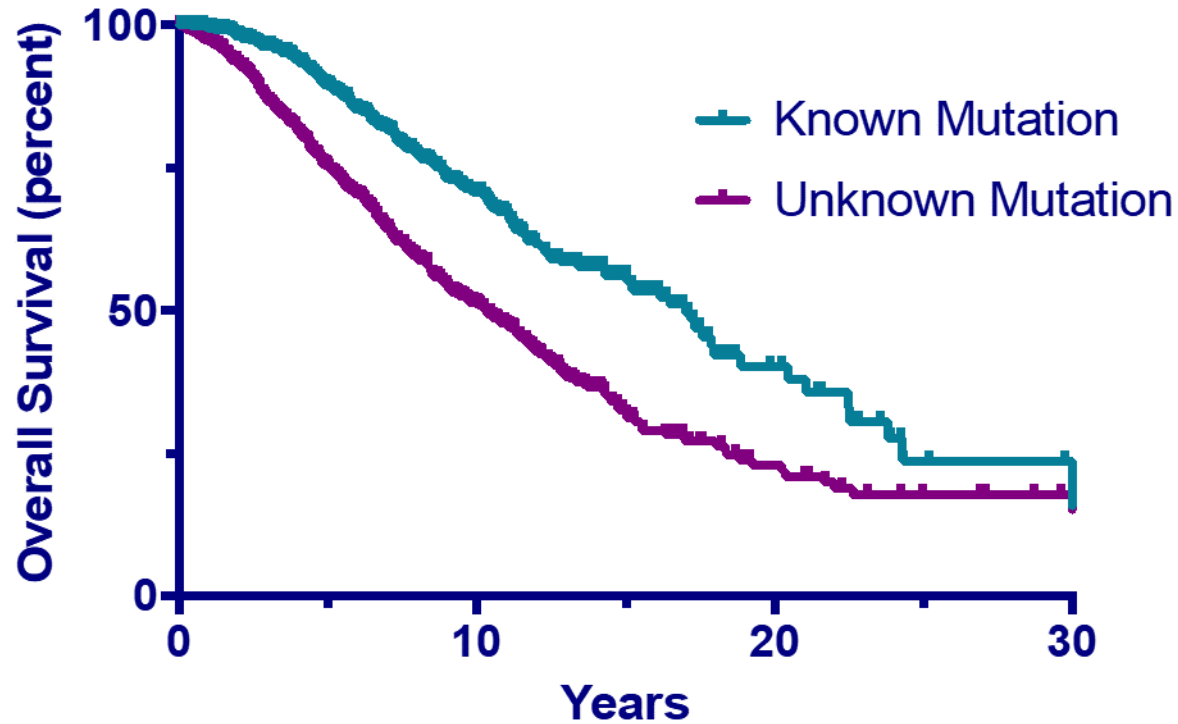


MUTATIONAL BREAKDOWN

KIT 78%
PDGFRA 8%
OTHER 14%



Overall Survival (yrs.), Known vs Unknown mutation



Reflects total patients in the LRG Patient Registry, US and non-US.

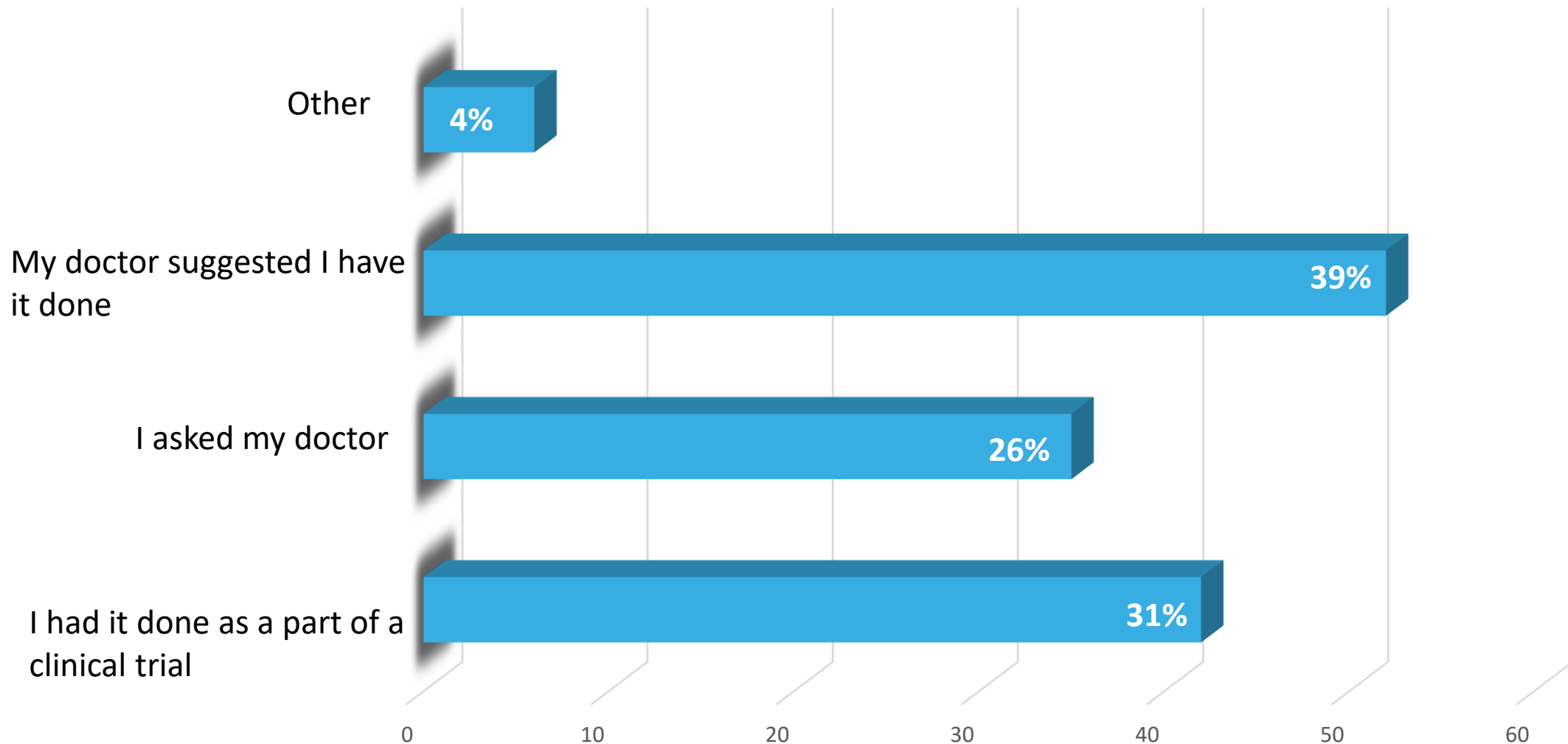
A variety of factors may confound this data:

- LRG members tend to be more pro-active in their care
- The LRG Tissue Bank Initiative encouraged testing
- Testing may not be available in other countries

	Don't Know Mutation	Know Mutation
LRG Patient Registry	970	739
Median survival	10.3 yrs	17.0 yrs



Why was mutational test done in your case?

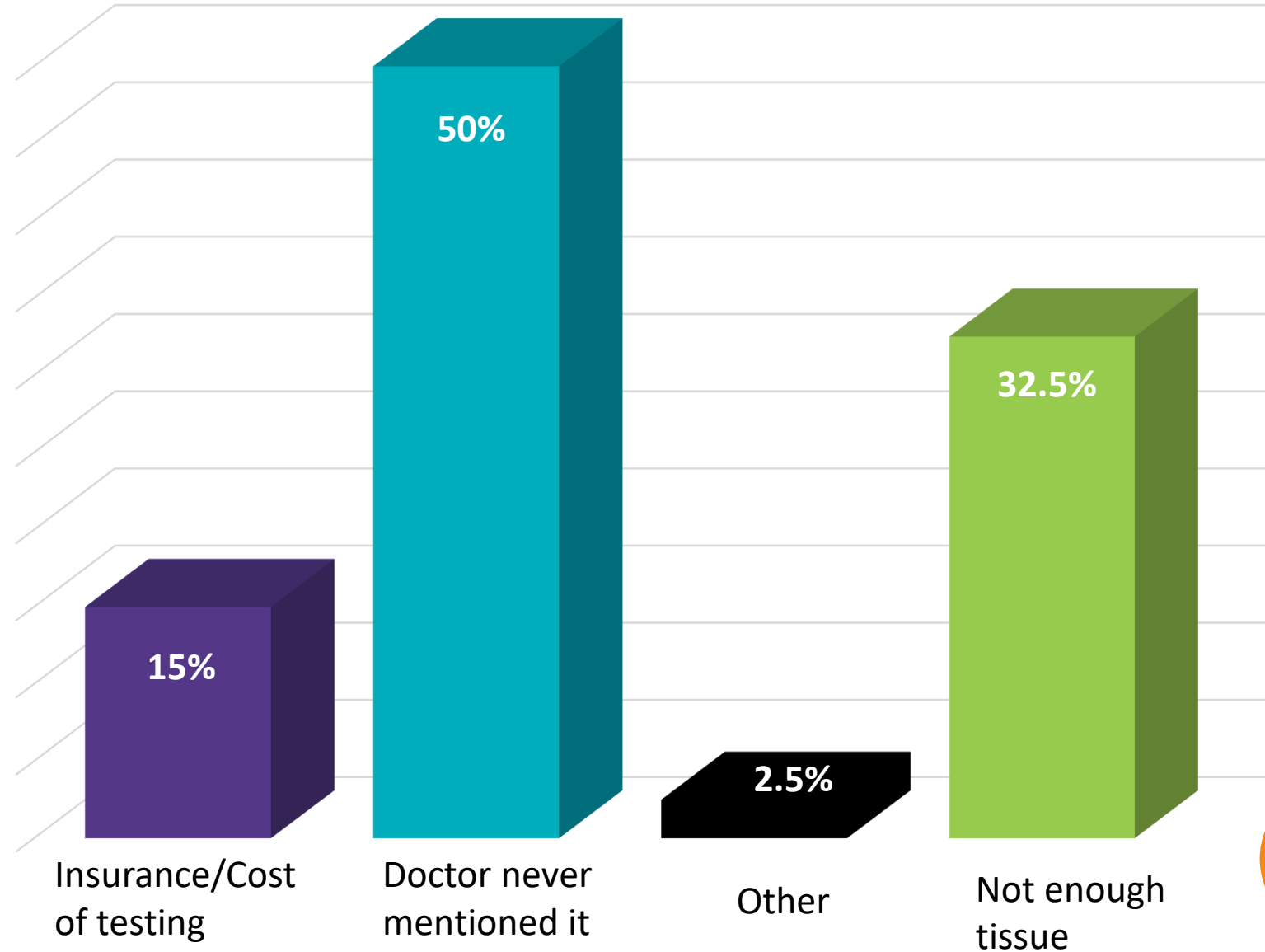


*graph from LRG mutational test survey



Why haven't you had mutational testing?

*graph from
LRG
mutational
test survey



Why is Real World Evidence important?



Rich diversity of data collected from large samples of patients will yield to a more precise, better targeted, and therefore a more highly effective health care.



Real world data and resultant real world evidence is being utilized to **enhance and complement traditional research**



RESEARCH EFFORTS

Diagnostic Algorithm for GIST – NCCN guidelines

- LRG produced a diagnostic algorithm in Sept 2018
- A global pathology sub-committee was formed
- Revising guidelines for primary GIST as well as molecular testing
- Guidelines were completed and submitted to the College of American Pathologists (CAP) and Association for Molecular Pathology (AMP) in Feb 2019



Publications

- **Genomic aberrations in cell cycle genes predict progression of KIT-mutant GIST**

Journal : Clinical Sarcoma Research, February 2019

- **Mutational testing in gastrointestinal stromal tumors**

Journal : Current Cancer Drug Targets, March 2019

- **Survival in advanced GIST has improved over time and correlates with increased access to post-imatinib TKIs**

Journal : Clinical Sarcoma Research, April 2019

- **Frequent Rectal GIST Recurrences in the Imatinib Era: Retrospective Analysis of an International Patient Registry**

- *Journal: Annals of Surgical Oncology, submitted April 2019*



THANK YOU!



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