

SALUD CON DATOS



New Horizons 2018
Vienna, Austria



Aims

Salud con Datos aims to gather representatives from disease advocacy organizations, medical professionals, industry representatives to discuss data sharing and data utilization across disease groups, institutions, and countries.

The vision is to identify areas to collaborate on the collection of data to learn more about our diseases and advance advocacy efforts in Latin America.



Background

- Identify GIST patients in LatAm countries
- No centralized GIST registry exists in LatAm
- Lack of data on socio-demographics, access, compliance, and health economics for cancer patients in LatAm

Goals

- Create a LatAM GIST Registry
- Close information gap by understanding needs of GIST patients in LatAm countries and translating data to health authorities, medical professionals, and patients via surveys, publications and presentations

Objectives

- Empowering participants to utilize data-driven evidence to help them make the case for health policies that will improve health outcomes.
- Establishing the credibility of evidence through peer-reviewed publications and poster presentations.
- Identifying and advocating for greater use of tools (such as patient reported outcomes) which capture the patient perspective in research.
- Developing a policy toolkit for members to encourage health authorities to put in place a regulatory policy environment that encourages clinical research and innovation in Latin America.

Anticipated Outcomes

1. An increase in the number of patients entered into patient registries in Latin American countries
2. Collaboration with academia to publish articles on patient-reported outcomes
3. Presentation of posters and publications at international conferences
4. Create a network to conduct clinical trials in Latin America

Local Data Projects

Argentina



Chilean GIST Registry

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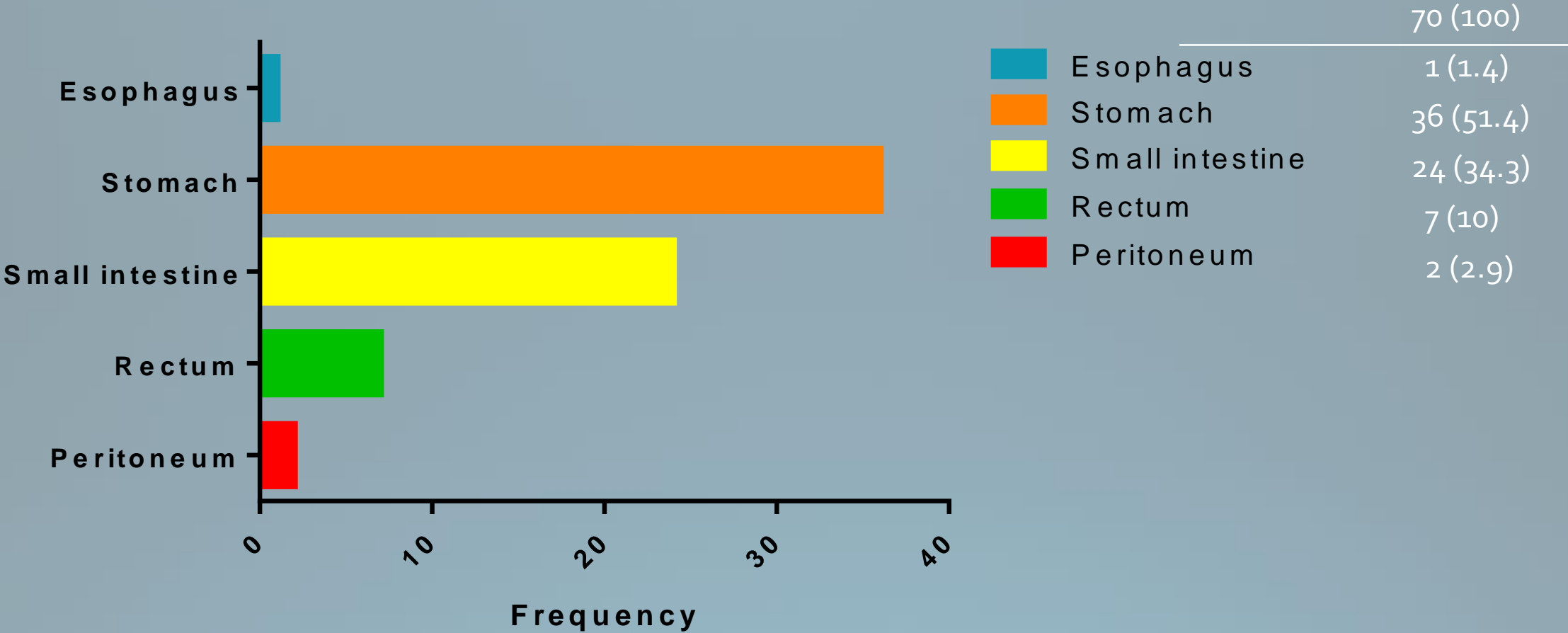
Demographic characteristics of GIST patients, April 2018

Variable	n (%)
Total patients	70 (100)
Gender	70 (100)
Male	25 (35.7)
Female	45 (64.3)
Median age at diagnosis	53 years (24-83)
Overall survival rate (OSR)	179 months
5-year survival rate	87%
Family cancer history	70 (100)
Yes	33 (47.1)
No	20 (28.6)
Not reported	17 (24.3)

Biological characteristics of GIST patients, April 2018

Variable	n (%)
Primary tumor site	70 (100)
Esophagus	1 (1.4)
Stomach	36 (51.4)
Small intestine	23 (32.9)
Rectum	6 (8.5)
Peritoneum	2 (2.9)
Uterus	2 (2.9)
Diagnostic finding	66 (100)
Primary tumor only	47 (71.2)
Multifocal primary tumor	6 (9.1)
Metastasis	13 (19.7)

Primary tumor site in GIST patients



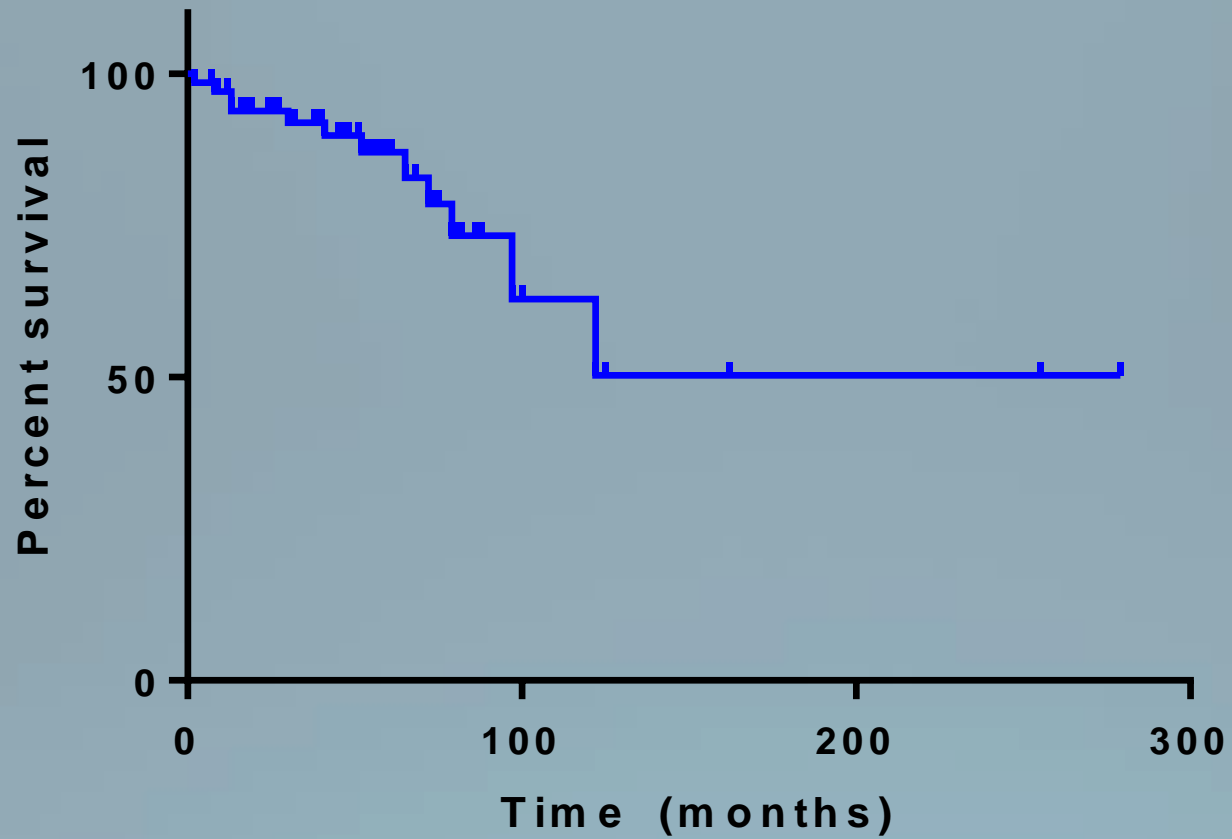
Biological characteristics of GIST patients, April 2018

Variable	n (%)
Mitotic index	52 (100)
0-2	19 (36.5)
3-20	25 (48.1)
>20	8 (15.4)
Mutational study	23 (100)
Only KIT mutation	10 (43.5)
Only PDGFRa mutation	6 (26.1)
KIT and PDGFRa mutation	2 (8.7)
Wild Type	5 (21.7)

Therapeutic characteristics of GIST patients, April 2018

Variable	n (%)
Surgery	70 (100)
Yes	60 (85.7)
No	10 (14.3)
TKI therapy usage	59 (100)
Imatinib	47 (79.7)
Sunitinib	8 (13.6)
Regorafenib	3 (5)
Pazobanib	1 (1.7)

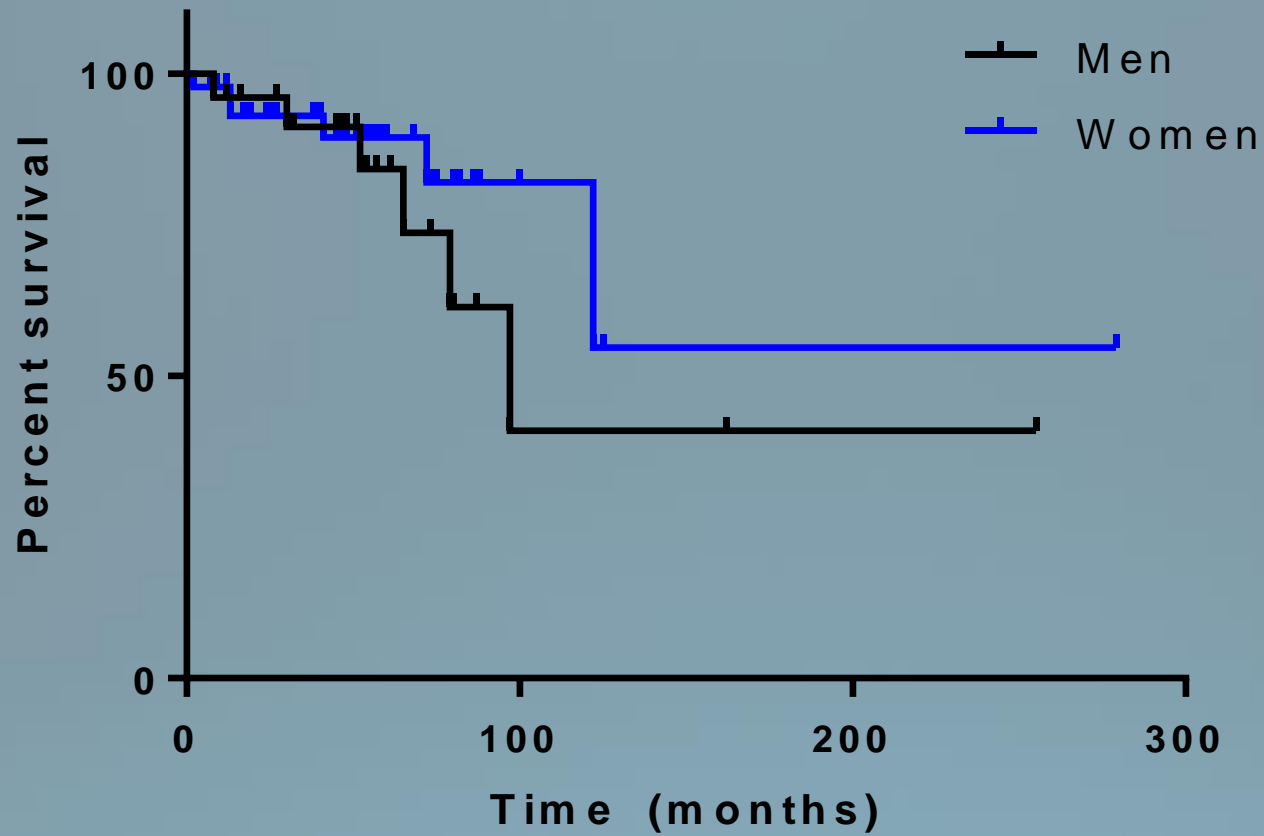
GIST patients Overall Survival



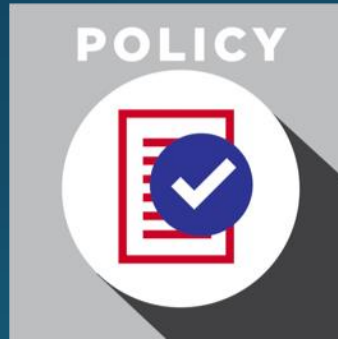
Median OSR

179 months

GIST patients OS by sex



Group	Median OSR
Men	97 months
Women	NR



Mexico



Fundación GIST México

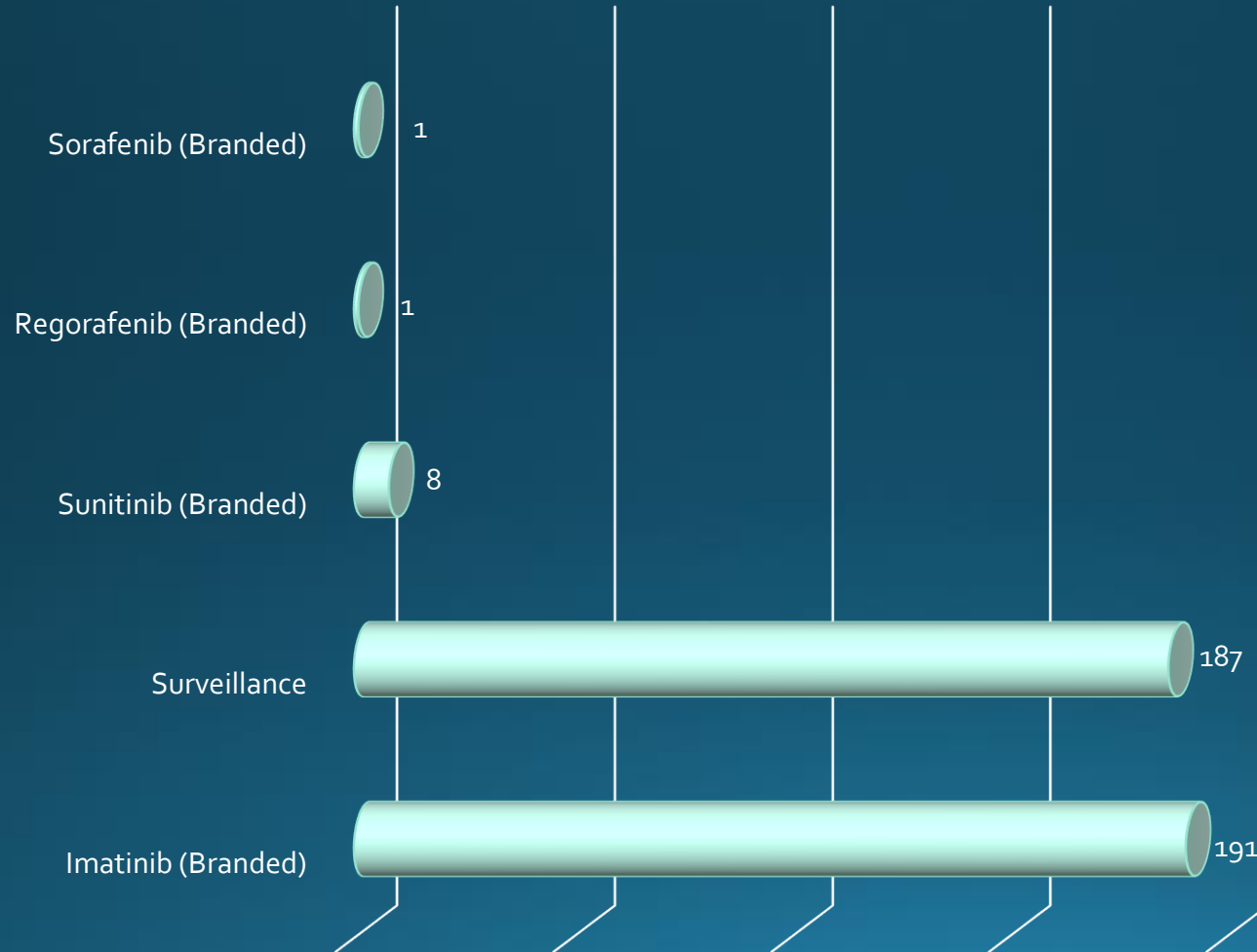


Guided and trained by the Life Raft Group, Fundación GIST México has started a local patient registry

Demographic characteristics of GIST patients, April 2018

Variable	n (%)
Total patients	421 (100%)
Gender	421 (100%)
Male	189 (45%)
Female	232 (55%)
Median age at diagnosis	53.3 years (12-81)
Overall survival rate (OSR)	180 months
Primary Tumor	421 (100%)
Stomach	220 (52.2%)
Small intestine	166 (39.4%)
Colon	18 (4.3%)
Others	17(4.1%)

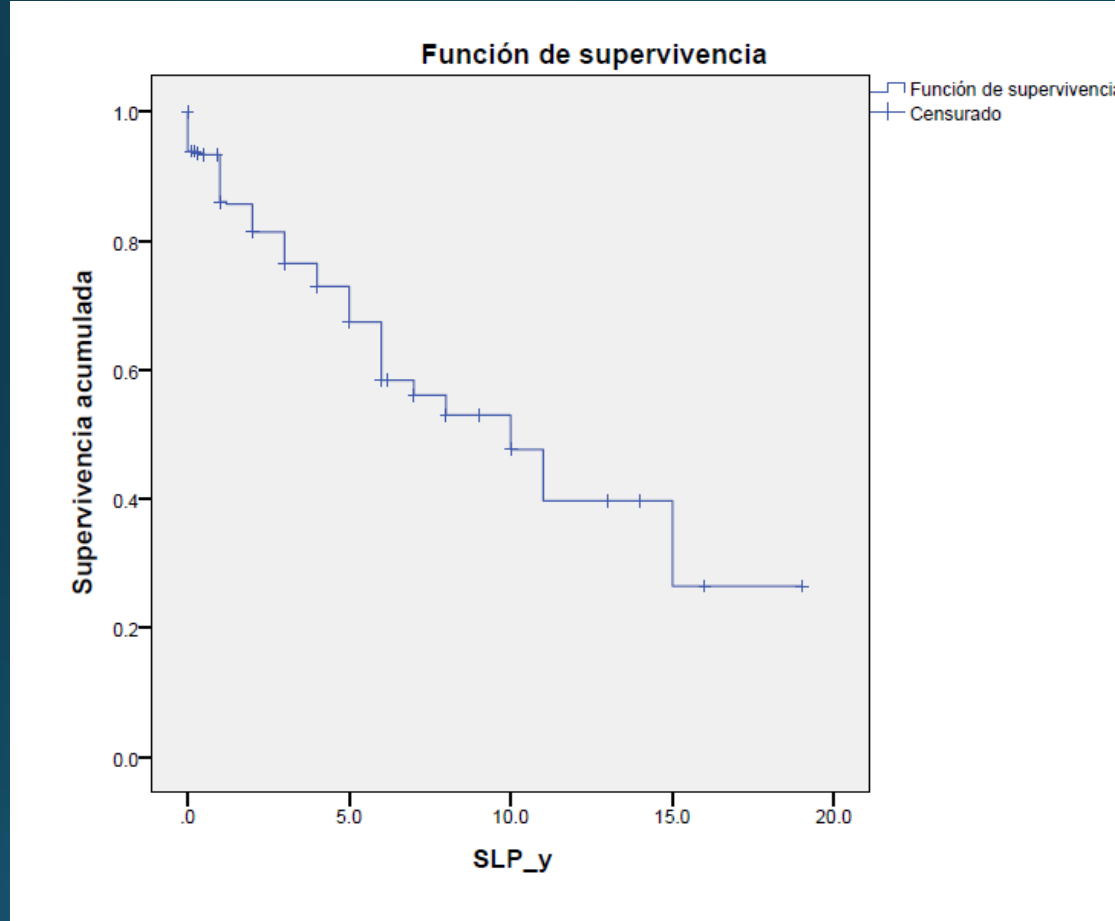
Medication



388 living patients

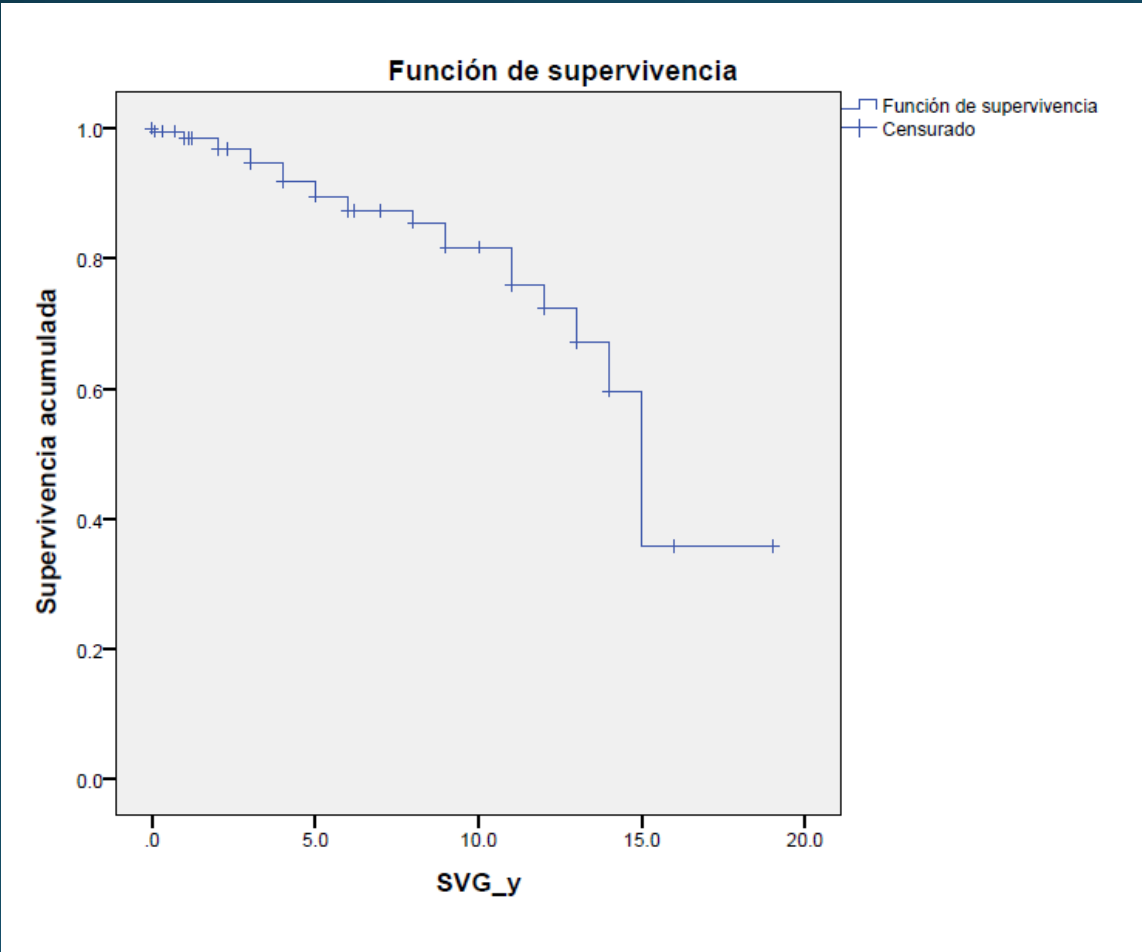


Progression Free Survival



***Median Progression
Free Survival:
10 years***

Overall Survival



***Median Overall Survival
from diagnosis:
15 years***

Outcomes






- Poster at ASCO meeting 2017: “Prognostic factors of recurrence and survival of Gastrointestinal Stromal tumors” with Dr. Rafael Medrano.
- Poster at the World Congress Gastrointestinal Cancer ESMO: “Epidemiological study of 414 Gastrointestinal Stromal Tumors (GIST)” and publication in Annals of Oncology with Dr. Germán Calderillo
- Poster at the XXIX National Congress of Research in Medicine: “Online Cognitive behavioral intervention and psychoeducation for patients with GIST: anxiety and depression” with Lic. Berenice Carbajal.
- Ongoing with Dr. Germán Calderillo: “Overall survival and long-term follow-up of 446 patients with gastrointestinal stromal tumors”.

How Salud con Datos Helped Mexico

- General Cancer Registry Project in our home state Nuevo León, population of 5.1 Million people.
- Approval of “Citizen Initiative” by general consensus in March 2018
- Meeting with leader of project at INCAN (National Cancer Institute) who is on board and excited to push project locally
- A state cancer registry is an excellent opportunity to identify patients who may benefit from clinical trials.

Top Research Interests



Argentina 	Chile 	Chile 	Mexico 	Mexico 
Impact of medical interventions in the natural course of diseases	Access to appropriate treatment	How many patients have GIST?	Median Overall Survival in patients with advanced GIST treated with systemic therapy	Who is getting sick?
Incidence and prevalence of common and uncommon tumors around the world	Real life toxicity	Where are the patients located?	Is toxicity similar than reported in other series?	What treatments are working well?
Expand data according Concord 3 trial published in Lancet last February	Economic impact of treatment	How are the patients doing?	Disease control similar than reported	What is the survival rate and why?

Outcomes of Salud con Datos



Clinical Trials

Collaboration

Build partnerships with
and discuss issues
regarding health data and
availability

Registries

Ways countries are
collecting data and
organizing it in a formal
way to analyze

Data

Tackling the issue of
health data availability
and quality in Latin
America