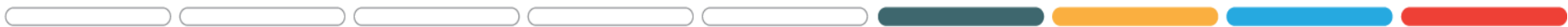


SOCIAL MEDIA-BASED DATA: FACEBOOK GROUP EXAMPLE

Toni Montserrat
PACIENTES LMC
SPAIN

Evidence Based Advocacy 1 -
Generating the evidence

#CMLHZ18

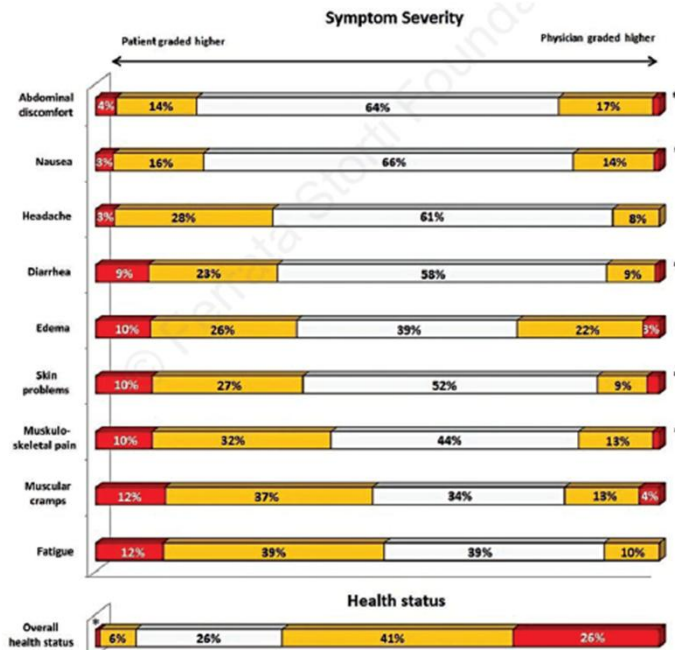


Generating the Evidence: Why? Objective?



Generating the Evidence: What kind of data and how?

Side effects, Quality of life



Form:

Side effects

Weight gain (from starting your treatment) *

Elige -

Weight loss (from starting your treatment) *

Elige -

Fever *

I haven't had any fever with the treatment

I had fever just when I started the treatment

I have frequently fever from the beginning of the treatment

Do you suffer from tiredness or fatigue? *

Yes

No

If suffering from tiredness to what degree does it affect your daily life?

1 2 3 4 5

A little A lot

Do you suffer gastrointestinal disorders? (Eg nausea, diarrhea vomiting, gastroesophageal reflux, bloating, pain in the side etc.?) *

Yes

No

If suffering from gastrointestinal disorders to what degree does it affect your daily life?

1 2 3 4 5

A little A lot

Do you suffer musculoskeletal disorders? (Eg muscle spasms and cramps, bone pain, swollen joints, etc.) *

Yes

No

If you suffer musculoskeletal disorders to what level will affect your daily life?

1 2 3 4 5

A little A lot

Do you suffer from disorders of the ear or the labyrinth (eg dizziness, hearing loss etc?) *

Yes

No

If you suffer ear disorders or labyrinth to what degree does it affect your daily life?

1 2 3 4 5

A little A lot

Do you suffer cardiac (eg tachycardia, arrhythmias etc.) disorders? *

Yes

No

In case of heart disorders to what level does it affect your daily life?

1 2 3 4 5

A little A lot

Do you suffer from any of the following - Headache, dizziness, memory impairment, etc nervous system issues? *

Yes

No

If you do have nervous system disorders to what level does it affect your daily life?

1 2 3 4 5

A little A lot

Do you suffer reproductive disorders and breast issues? (Eg. Erectile dysfunction, irregular menstruation, breast pain, scrotal edema, etc.) *

Yes

No

In case of having reproductive disorders / menstruation issue to what extent does it affect you day?

1 2 3 4 5

A little A lot

Do you suffer from disorders of the skin and subcutaneous tissue? (Example pruritus, dry skin, erythema, alopecia, photosensitivity reactions, psoriasis, purpura, etc.) *

Yes

No

If you suffer skin disorders and subcutaneous tissue issues to what level does it effect your daily life?

1 2 3 4 5

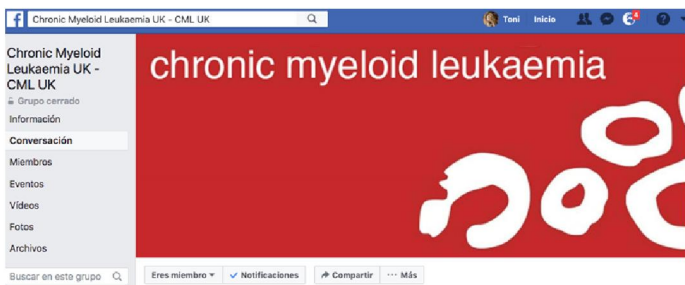
A little A lot

Patient- versus physician-reporting of symptoms and health status in chronic myeloid leukemia . Fabio Efficace – Haematologica 2014; 99(4) doi:10.3324/haematol.2013.093724

Generating the Evidence: Which tools?



COLLABORATE!!!



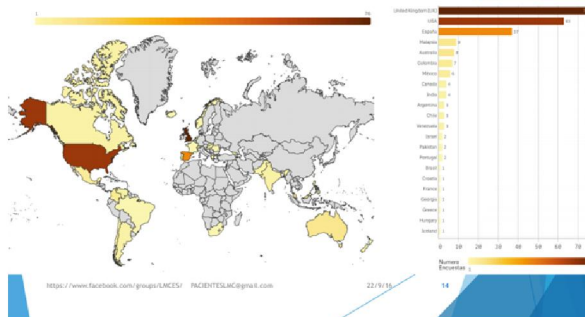
- ✓ Draft
- ✓ Survey in Spanish
- ✓ Translate to English
- ✓ Share through FB and TW
- ✓ Store answers on database



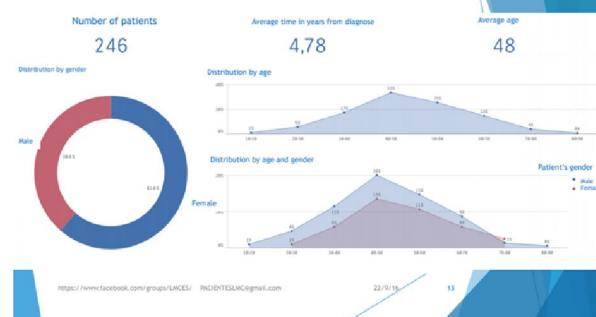
Generating the Evidence: How analyse the data? Someone's help?



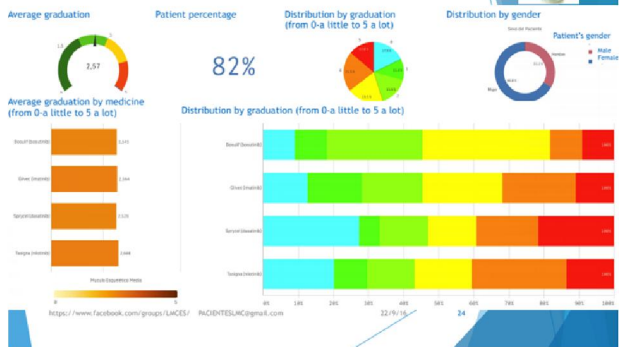
Geographic distribution



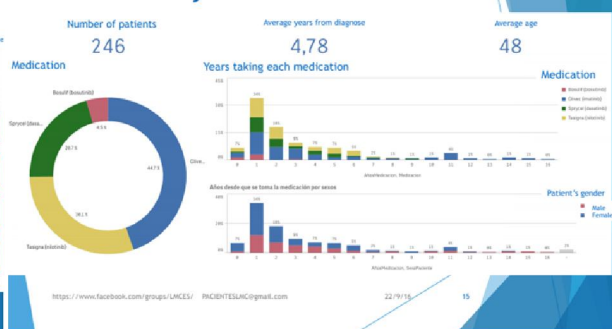
General data



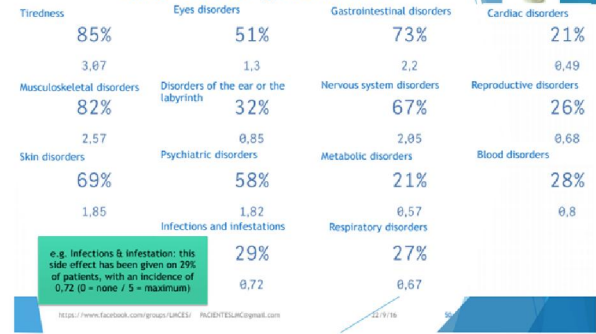
Musculoskeletal disorders



By medication, age and years of treatment



Global results: % of patients and side effect graduation

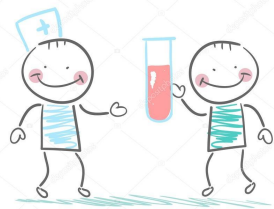


Generating the Evidence: How use the data? Publish the data?

SURVEY RESULTS:



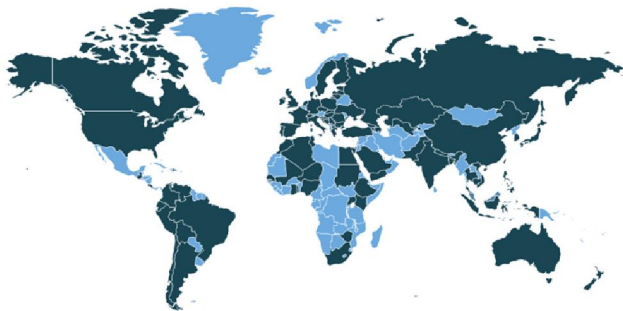
<https://goo.gl/YuFYVi>



haematologist



Facebook CML Horizons
Twitter EHA Meeting
Email ...



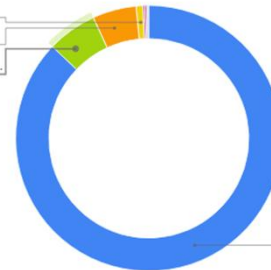
CML ADVOCATES Network

English

Total Clicks
2,204

Referrers

t.co 0.8%
unknown 5.3%
www.facebo... 6%

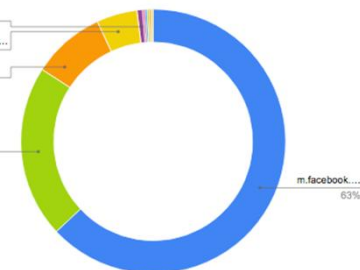


Spanish

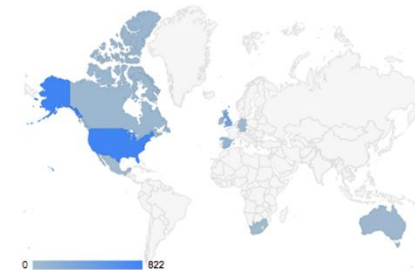
Total Clicks
763

Referrers

goo.gl 0.7%
www.facebo... 5%
t.co 8.9%
unknown 21.1%



Countries



Countries



Generating the Evidence: What did it cost ?

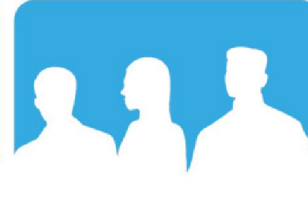


If there's no money...



Ideas

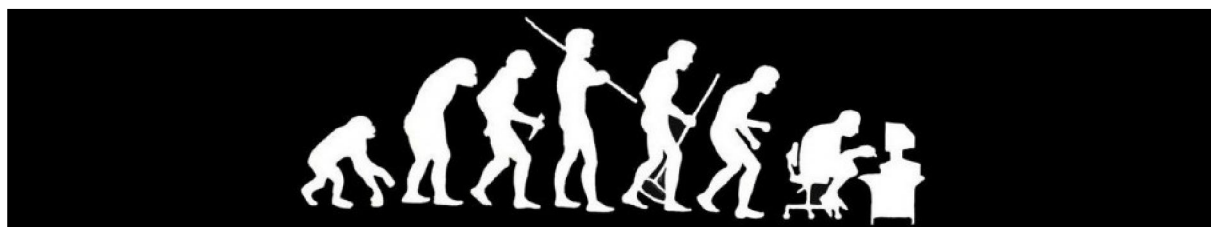
- +Patient Experience
 - +Patient Advocacy
 - +Collaboration
 - +Online Free Tools
 - +Time
- = Results → Evidence



Generating the Evidence: what would do differently next time?



Learn. Share. Grow.



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[@LMC_PACIENTES](https://www.instagram.com/LMC_PACIENTES)