

SURVEY

PATIENT-TO-PATIENT

RE: SIDE EFFECTS

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Advocacy Session #4
Best practice in patient advocacy
#CMLHZ17



CML: A RARE DISEASE WITH FAST EVOLUTION, However with a side effect profile that is not know by patients

- CML has changed from being a fatal disease to a chronic one in the past 15 years
- Five targeted therapy drugs are available (TKI's)
- What as yet has not been assessed in detail, in our view, is the real impact of this class of drugs on our different lives due to their relatively recent introduction.
- There have been studies by the pharmaceutical industry, but we believe it is important to have real and objective opinion from patients.



+ *Team*
 + *Organization*
 + *No money*
 + *Time*
 = *Info QoL*



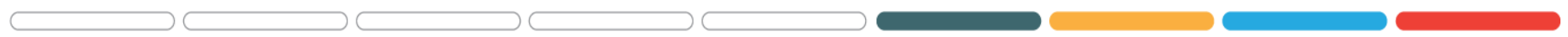
Creating a survey from patient-to-patient (I)

Expertise on CML → our colleague with a greater time on TKI's (over 17 years) gave us guidance for the survey.

Expertise on IT → to have the best results, you need someone used to working with the IT tools, and to assure the integrity of process and results.

Expertise on English → we wrote the survey in Spanish, but help was given with translation by a British CML advocate (Thanks Nigel!) translating it to avoid misunderstandings

Expertise on Social Network → as rare as CML is, it's necessary to reach as many of patients around the world. Facebook support groups have been a great help.



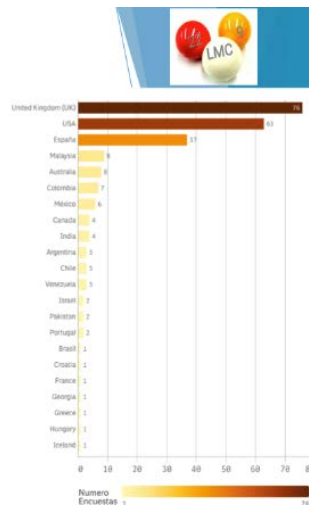
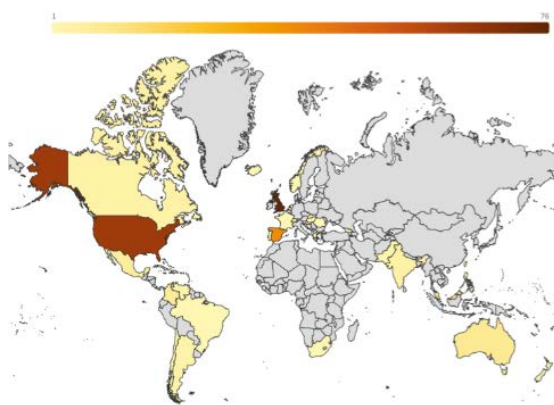
Creating a survey from patient-to-patient (II)

Expertise? → we do not have a high profile or knowledge...mainly we have been wanting to help, and so had some ideas about how to do this.

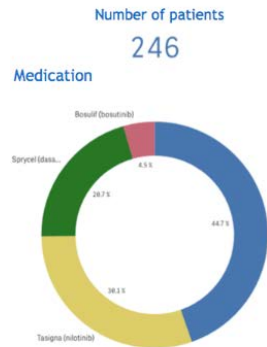
Learning by doing → after creating our first survey, and being pleased with information and results given, we are rightly proud of having this...but also realized that some issues could be improved.

Our special thanks to the friends of ASPHER-Aragón and CML-UK who have participated actively in this project.

Geographic distribution



By medication, age and years of treatment



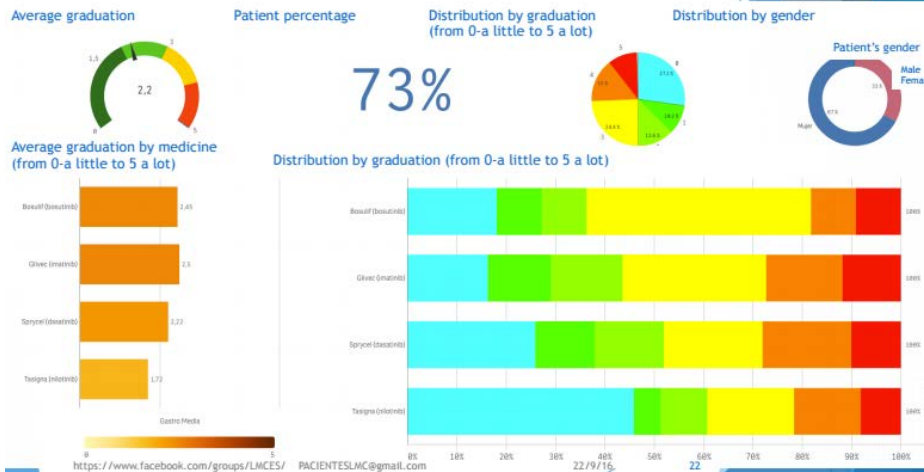
Result and Impact:

We received 246 answers → the results have been viewed over 2.600 times.

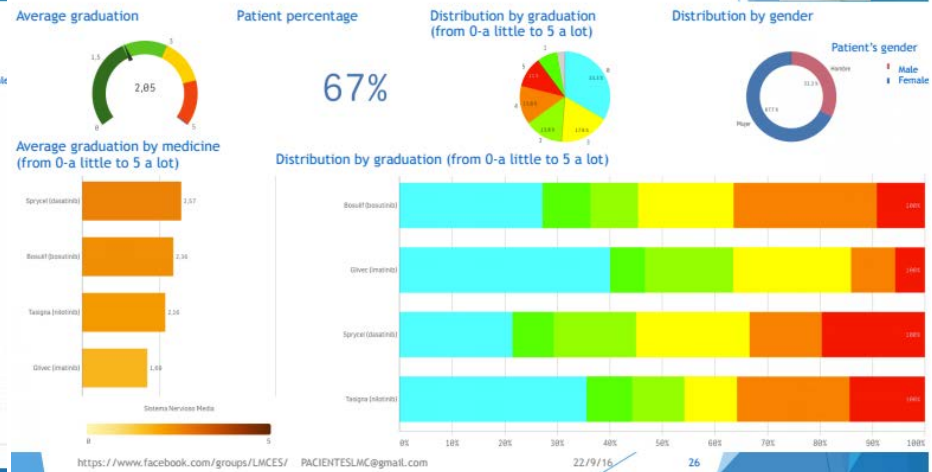
Several patients in Spain have shared it with their Haematologists to help them to understand us better. Some of them are still denying the evidence.

As patient, we also feel better once we realize we are not alone, we are not crazy...at least not totally 😊

Gastrointestinal disorders

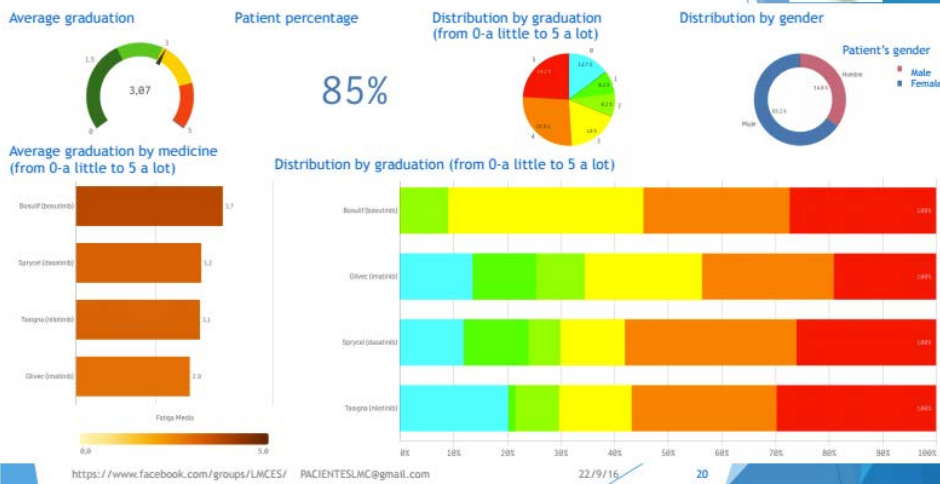


Nervous system disorders

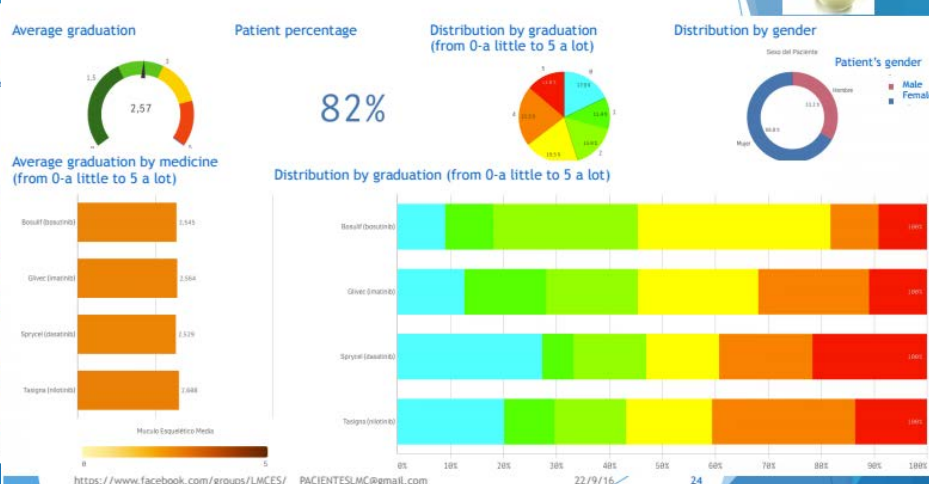


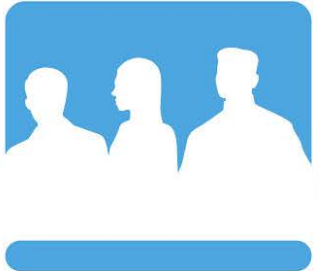
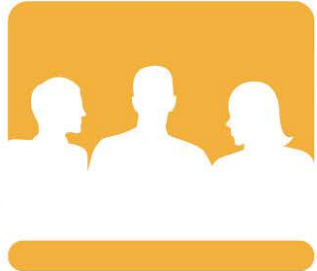
Result and Impact:

Tiredness or fatigue



Musculoskeletal disorders





Conclusion and recommendation:

Under the umbrella of the CML Advocates Network, **TOGETHER** we are **STRONGER!**

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Global results: % of patients and side effect graduation



Tiredness	Eyes disorders	Gastrointestinal disorders	Cardiac disorders
85%	51%	73%	21%
3,07	1,3	2,2	0,49
Musculoskeletal disorders	Disorders of the ear or the labyrinth	Nervous system disorders	Reproductive disorders
82%	32%	67%	26%
2,57	0,85	2,05	0,68
Skin disorders	Psychiatric disorders	Metabolic disorders	Blood disorders
69%	58%	21%	28%
1,85	1,82	0,57	0,8
Infections and infestations	Respiratory disorders		
29%	27%		
0,72	0,67		

e.g. Infections & infestation: this side effect has been given on 29% of patients, with an incidence of 0,72 (0 = none / 5 = maximum)

<https://www.facebook.com/groups/LMCES/> PACIENTESLMC@gmail.com

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SURVEY RESULTS:



<https://goo.gl/YuFYVi>

