



INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY
LYON, FRANCE | OCTOBER 23-26, 2019

51ST CONGRESS OF THE INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY

LYON, FRANCE OCTOBER 23-26, 2019



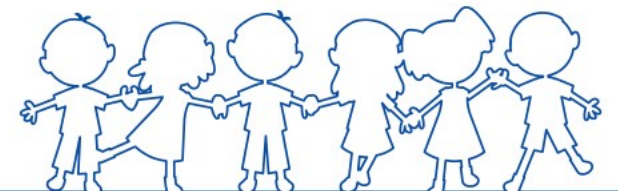
In conjunction with:



No child should die of cancer

Research about childhood cancer

- **Survey** : What topics and answers are parents and patients looking for ?



WHERE ?

HOW MANY?

WHO ?

52

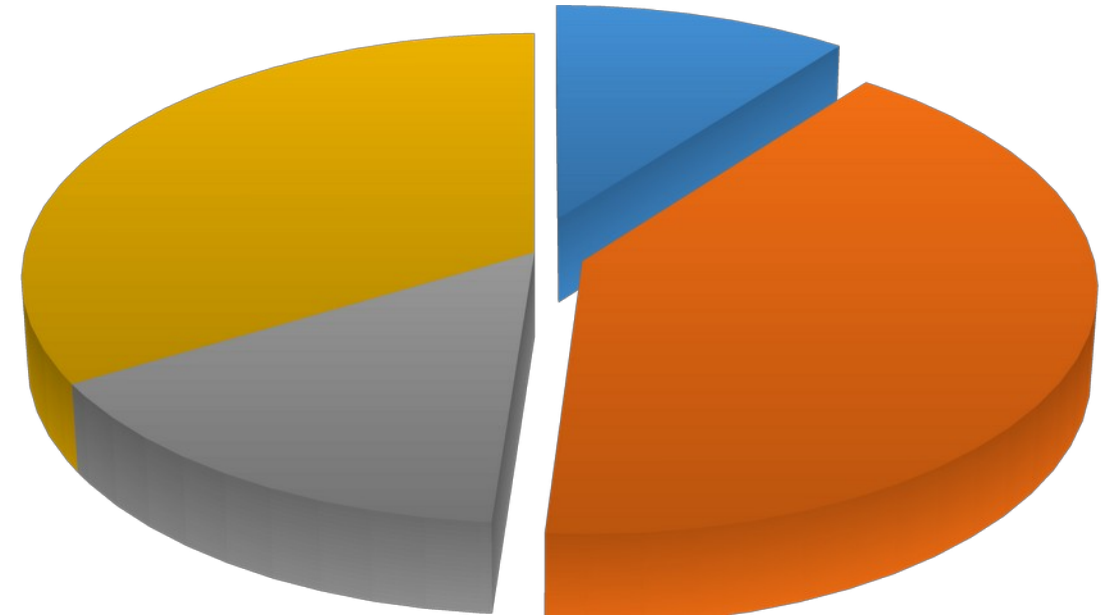
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- Africa : 13
- America : 9
- Asia : 14
- Europe : 61
- Oceania : 1

98

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- Former patient
- Close relative (father, mother, sibling)
- Caregiver or Research
- NGO volunteer or close

No child should die of cancer

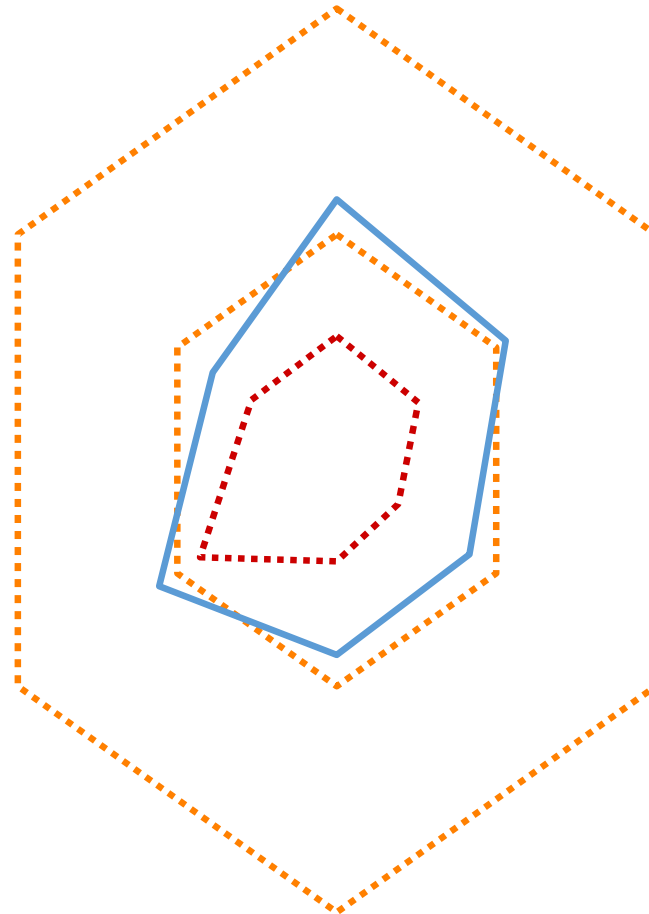


Where are the GAPS ?

Children specific innovation

Adaptation of adult innovative treatment

Late effects



— Should be

... Is done

Improvement of current treatments

Research about causes

Research about genetic

No child should die of cancer



More research seen outside Europe ?

Children specific innovation

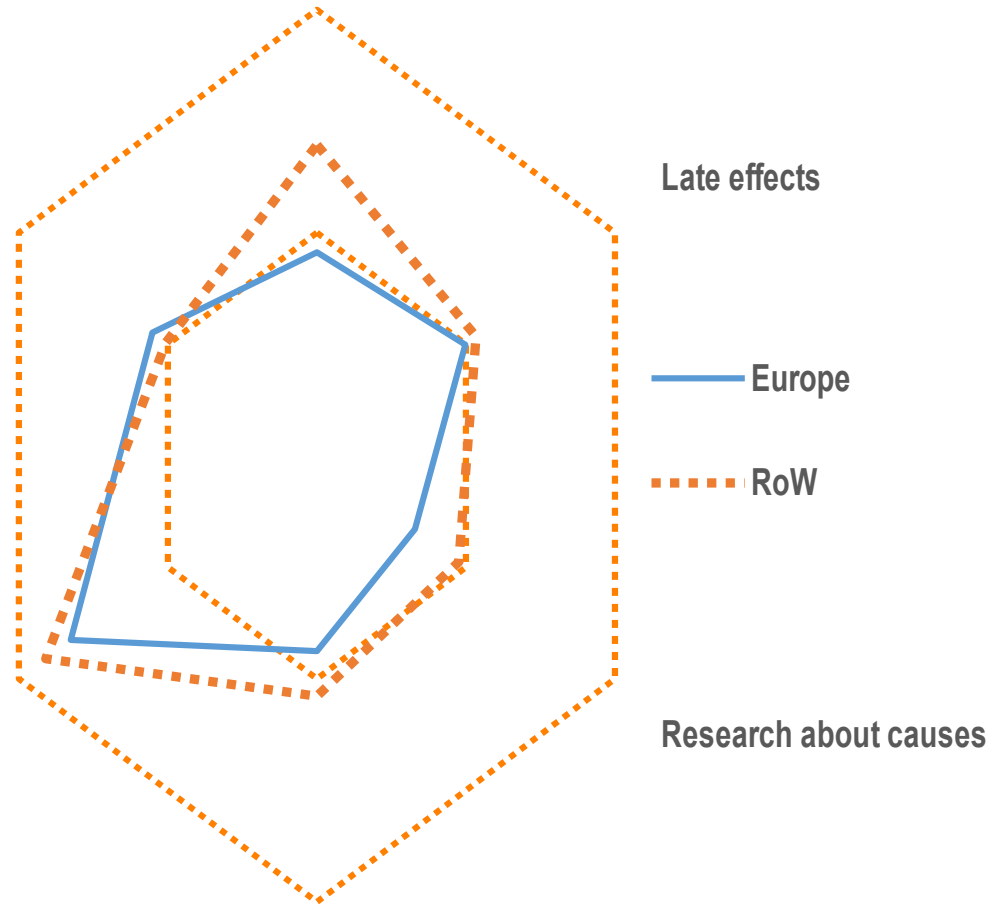
Adaptation of adult innovative treatment

Late effects

Improvement of current treatments

Research about causes

Research about genetic



— Europe

- - - RoW

No child should die of cancer



What do we understand ?

35% of respondents did not rate all the word

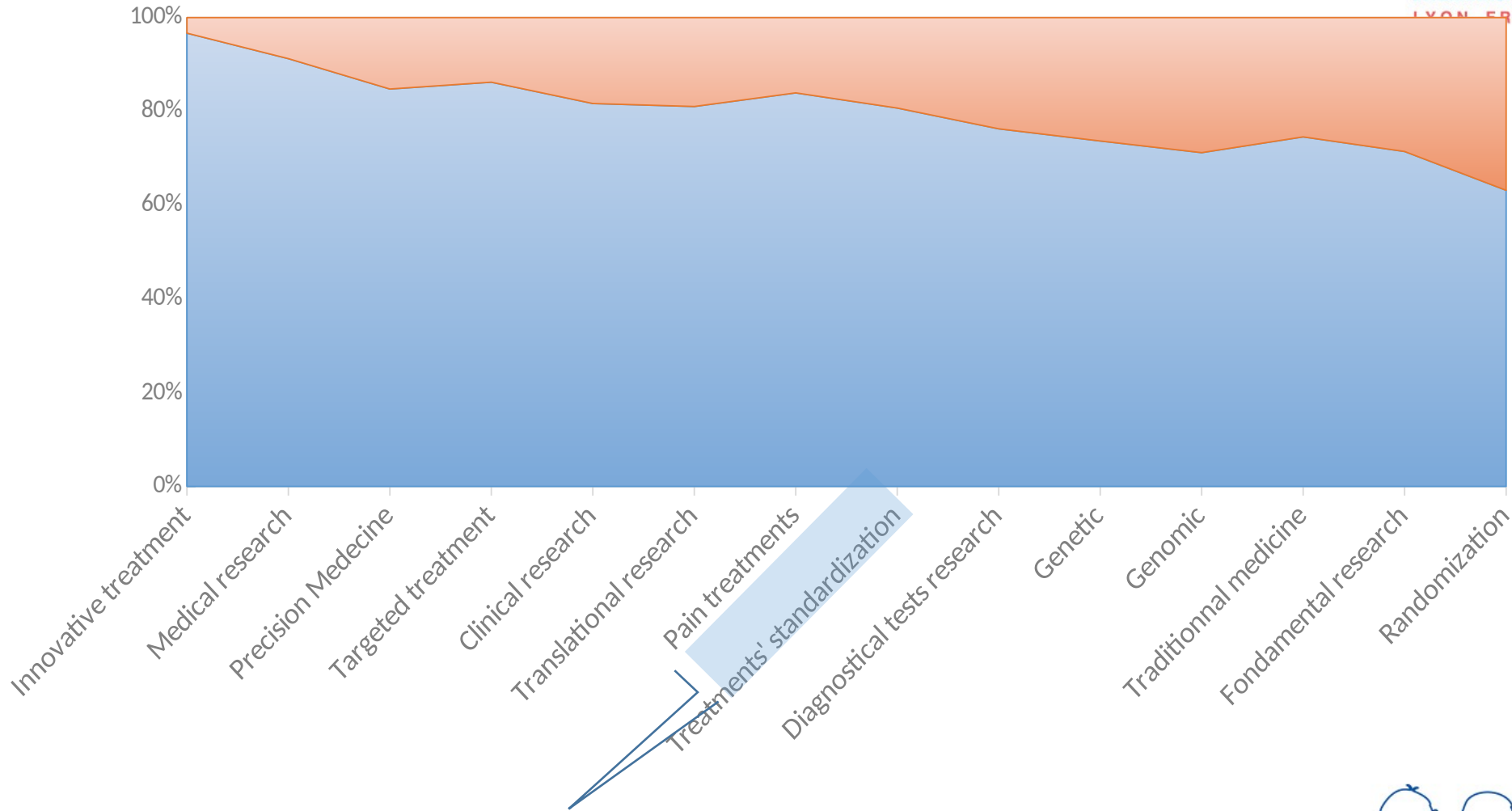
- Less than 50% of answerers understand the words :

	Global	Without Healthcare Professionals	without Europe	French survey (2016)
Translational research	32%	31%	37%	17%
Fondamental research	38%	39%	41%	46%
Genomic	38%	39%	45%	35%
Randomization	45%	44%	34%	40%
Precision Medecine	51%	49%	50%	> 80%

Highest score : More than 83% understand « Pain treatments »



What topics do we want to learn more about ?



Randomization is not an issue ?

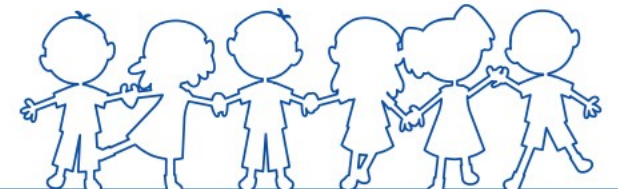
But still 84% would like to learn more about « Pain treatments »

No child should die of cancer



What do we understand when involved in a trial ?

- 24% of the respondents took part in a research study
- 29% of them still have questions
- 78% didn't answer « Yes » to the question :
 - 65% if you consider those who answered « Yes, partially »
 - “ Were the written documents you received useful ? Were they clear ? “
- 65% didn't get informations about the results and 39% even lost contact



Where do we find informations :

• National Institutional websites	33,33%	22,22%	13,33%	11,11%	13,33%	0,00%	6,67%
• International Institutional websites	31,11%	31,11%	6,67%	11,11%	6,67%	6,67%	6,67%
• The departement which treated your child	15,00%	22,50%	25,00%	22,50%	5,00%	2,50%	7,50%
• Your usual doctor or specialits	17,65%	7,84%	19,61%	15,69%	25,49%	9,80%	3,92%
• Parents organization members involved in the research	5,17%	15,52%	13,79%	20,69%	17,24%	20,69%	6,90%
• Communication websites (Forum, personnal blog, ...)	5,66%	3,77%	16,98%	15,09%	9,43%	30,19%	18,87%
• A close friend or a member of your family	8,62%	6,90%	10,34%	8,62%	5,17%	18,97%	41,38%

Outside Europe (n=21)

• National Institutional websites	50,00%	16,67%	0,00%	16,67%	8,33%	0,00%	8,33%
• International Institutional websites	26,67%	33,33%	6,67%	6,67%	13,33%	6,67%	6,67%
• The departement which treated your child	7,69%	7,69%	38,46%	23,08%	15,38%	0,00%	7,69%
• Your usual doctor or specialits	5,88%	11,76%	29,41%	5,88%	29,41%	11,76%	5,88%
• Parents organization members involved in the research	17,65%	0,00%	23,53%	17,65%	11,76%	5,88%	23,53%
• Communication websites (Forum, personnal blog, ...)	4,76%	19,05%	4,76%	23,81%	9,52%	28,57%	9,52%
• A close friend or a member of your family	11,11%	5,56%	11,11%	5,56%	0,00%	33,33%	33,33%

