

Unmet needs in Information on NETs

INCA - the global voice in support of neuroendocrine cancer patients

20 patient advocacy & research groups

in 17 countries



Asia, Asia Pacific, Europe & North America

Online survey results



NET patient leaders
35 responses



NET patients and family
338 responses



Healthcare professionals
70 responses



Information gaps

NET patients' needs for information on these matters were not at all met at the time of diagnosis¹



According to patients:	Percentage	Topic	Percentage	According to healthcare professionals:
	53%	relevant clinical trials	6%	
	53%	NETs research	6%	
	19%	medical condition	2%	
	44%	patient associations	4%	

Needs for information on psychological care



Over half of the NET patients and patient leaders said the needs for information on psychological care were not at all met²

Lack of information on how to manage the condition

one third state that³



diet



symptom control



exercise

information is key



Lack of information on treatment options

only 16% can make informed decisions⁴



INCA survey shows:



More resources for vital support



Partnership is key



"If you don't suspect it you can't detect it"