

Unmet needs in basic understanding of



Shared view



Patient and medical communities should support each other to ensure:

- global collaboration for clinical trials
- international data registries
- more funding from governments and industry

Come join us at the second INCA-ENETS Symposium

"UNMET NEEDS OF NET PATIENTS: FROM IDENTIFICATION TO ACTION"

March 9 9:35 am Meeting Room 111 at CCIB

A collaborative effort by NET patient and medical leaders, the symposium aims to address issues that impede optimal care and research, and will feature:

- an overview of NET Cancer Day and the INCA White Paper on Unmet Needs in NETs launch
- a rich selection of perspectives on the **information NET patients need** to have and the benefits of **patient involvement in research**,
- offered by **NET patients, expert clinicians and NET nurse specialists.**

If you are interested in these key topics, we hope to see you at the INCA-ENETS Symposium at **9:35 am on March 9, Friday.** Lunch will be served at 12:40.



Partnership is the key



INCA FULL MEMBERS: • A.I.NET, *Italy* • AMEND, *UK* • APOZ, *Bulgaria* • APTED, *France* • Carcinoid Cancer Foundation, *USA* • CarciNor, *Norway* • CARPA, *Sweden* • CNETS, *Canada* • CNETS, *India* • CNETS, *Singapore* • NET Patient Foundation, *UK* • NET Patient Network, *Ireland* • NET Research Foundation, *USA* • Netzwerk Neuroendokrine Tumoren, *Germany* • Netpa, *Denmark* • PanCAN Japan, *Japan* • Pheo Paratroopers, *USA* • The Unicorn Foundation, *Australia* • The Unicorn Foundation, *New Zealand* • VZW NET & MEN Kanker, *Belgium*



The Global Voice for NET Patients

INCA – the global voice in support of neuroendocrine cancer patients

20 patient advocacy & research groups

in 17 countries



Asia, Asia Pacific, Europe & North America

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 met

INCA survey shows:



INCA unmet needs in NETs Assessment Survey among key stakeholders

In-depth interviews with 20 patient and medical leaders
Online surveys in 26 countries



NET patient leaders
35 responses



NET patients and family
338 responses



Healthcare professionals
70 responses



Lack of information on how to manage the condition

one third state that:



diet



symptom control



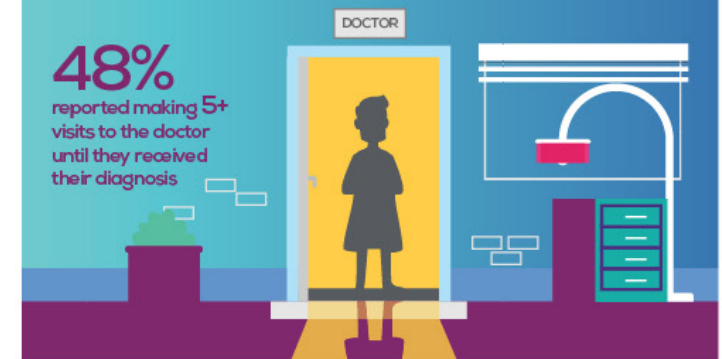
exercise

information is key



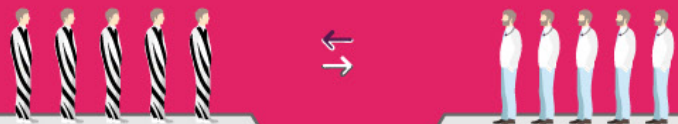
Receiving the correct diagnosis

48% reported making 5+ visits to the doctor until they received their diagnosis



Information gaps

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



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

Lack of information on treatment options

only 16% can make informed decisions



Almost 50% of all patients have travelled more than 300 km/186 miles to see a NETs specialist

This impacts on patient outcomes
Huge financial and emotional stress to patients and families

