

Unmet needs in the global NETs patient community: an assessment of major gaps from the perspectives of patients, patient advocates and NET health professionals

CONTRIBUTORS:

Bouvier, C; Caplin, M; Conroy, S; Davies, P; Dureja, S; Falconi, M; Ferolla, P; Fisher, G; Goldstein, G; Hicks, R; Hollander, R; Kolarova, T; Lawrence, B; Leyden, S; Majima, Y; Metz, D; O'Toole, D; Ruzniewski, P; Wiedenmann, B.

Abstract

The International Neuroendocrine Cancer Alliance (INCA) is a global alliance made up of 20 patient advocacy and research groups in 17 countries from Asia, Asia Pacific, Europe, and North America. Its work is focused on supporting country member organisations and, through them, supporting neuroendocrine cancer patients (and their families) and advocating on their behalf to improve diagnosis, care and research.

The assessment INCA has conducted has identified important unmet needs in the provision of information to patients at diagnosis; in essential services and multidisciplinary care; in access to innovative diagnostics and treatment; and a lack of patient involvement in research strategies and clinical trials. While it is not uncommon for some of these gaps to exist for patients with other forms of cancer, they are particularly vexing for neuroendocrine patients for several reasons including:

- late diagnosis: as noted below, NET patients are typically misdiagnosed (and often inappropriately treated) for years. Once diagnosed, their tumors have often metastasized making treatment more challenging and options more limited and difficult.
- Neuroendocrine tumors (NETS) can be quite heterogeneous. They can occur in a wide variety of sites. They can be quite indolent and yet become very aggressive. The same tumor type and site may respond very differently in “similar” patients.
- Despite some recent progress, there are still limited treatment options available and no cure. And while early detection and surgical removal of a small “primary” NET may be “curative” for some, few patients are diagnosed and appropriately referred to an expert multi-disciplinary team early enough...
- many other factors that make NETs management particularly challenging: different stages and grades affecting survival, complications such as carcinoid heart disease & bowel ischemia, related syndromes to different NET types, etc.

Given these conditions, gaps in reliable information, in access to NET specialists and state-of-the-art care, and in advancing critical research are significant and troubling. Some of these concerns are global, while others may vary by country and healthcare system.

The resulting shortcomings in care may be unnecessarily affecting patient outcomes by decreasing the opportunities for effective treatment and management of the disease. Unmet needs in research are also negatively impacting the medical and scientific community's ability to develop a better understanding of NETs and a future with improved diagnostic and treatment options.

Patient support and advocacy groups have a key role to play, working in partnership with the medical community in addressing these problems. The research reveals consensus on many critical needs by both groups and has also identified differences in perception between patients and health professionals, thus illuminating areas where greater collaboration is needed.

This initiative is premised on the belief that both NET patients and healthcare professionals share a deep commitment to support each other, to better understand these unmet needs, and to work together to enhance and improve access to the information, patient care, and research that all NET patients deserve no matter where they live in the world.

There is an urgency attendant to this work: the numbers of people diagnosed with NETs seems to be increasing at a significant rate. The latest study on Neuroendocrine tumor demographics finds that seven in every 100 000 people are diagnosed with NETs each year. The same study finds that the incidence of NETs has increased almost seven fold between 1973 and 2012ⁱ. While the reasons for this increase are not entirely known, most NET experts believe that better awareness has led to earlier (better) diagnosis in recent years and that this trend (rather than a sudden increase in incidence) may play an important role.

In the INCA survey, forty eight percent of patients reported making five or more visits to the doctor before receiving their NET diagnosisⁱⁱ. Over half of NET patients are diagnosed when the disease has advanced due to misleading symptoms leading to misdiagnosis. Forty-five percent (45%) of patients report not receiving NETs as the first diagnosis, with the most common initial diagnosis being a digestive disorder, for example Irritable Bowel Syndrome (39%).

The objectives of the INCA assessment were to:

- increase understanding of the perceptions of unmet needs on behalf of patients, patient group leaders and health professionals.
- establish an evidence base on unmet needs so that the global NETs community can identify priorities for action that will improve the care of patients, and better prospects for improved health outcomes.
- provide a platform for discussion with the medical community which can lead to a collaborative effort to tackle the unmet needs identified.
- identify those unmet needs that are common to many countries and which have a global perspective.
- identify solutions where working as a team, patients, advocates and NET specialists can make a crucial difference in the lives and prospects of NET patients around the world.

ACKNOWLEDGEMENTS:

This White Paper, and the survey and interview process on which it is based, were made possible by a grant from the Neuroendocrine Tumor Research Foundation, a non-profit, charitable foundation dedicated to NET research and support of NET patients.

INCA would like to thank Board members of the key international medical societies ENETS (European Neuroendocrine Tumor Society), NANETS (North American Neuroendocrine Tumor Society), APNETS (Asia-Pacific Neuroendocrine Society), CommNETs (Commonwealth Neuroendocrine Tumor Group) and JNETS (Japan Neuroendocrine Tumor Society) who kindly contributed their time and expertise.

Methodology

Three surveys were completed using an on-line survey tool between February 15, 2017 and March 1, 2017; one for patients and family, a second for healthcare professionals, and a third for leaders of patient advocacy or support groups (69% of these patient leaders are NETs patients themselves). There were 35 questions across four key areas of investigation; information, standards of care, access to diagnostics and treatment, and research. Data from the first Global NETs Patient Survey in 2014ⁱⁱ, was used to support the identification of unmet needs explored by the surveys. Questions were designed to be comparable.

In total, there were over 400 respondents drawn. This may cause selection bias towards “enlightened” patients and healthcare professionals from the developed world, but this was nevertheless considered to be valid in order to derive views from knowledgeable and engaged respondents. To the extent that such participants are already both more informed and connected to the NET community, the resulting assessment of “unmet needs” is probably understated. The survey was also disseminated to health professionals by INCA member organizations and patient group leaders. As such, the health professionals participating can be taken to be those directly involved in NETs treatment. Responses were received from 26 different countries, as follows:

Patient advocate/leader survey – 35 responses

Patient and family survey – 338 responses

Healthcare professionals survey – 70 responses (see distribution of specialties below)

Q2: What is your medical expertise?

Answer Choices	Responses
Oncology	38.57% 27
Pathology	1.43% 1
Radiology	1.43% 1
Nuclear medicine	12.86% 9
Endocrinology	8.57% 6
Surgery	10.00% 7
Gastroenterology	28.57% 20
Nurse	10.00% 7
Pulmonologist	0.00% 0
Other (please specify)	4.29% 3
Total Respondents: 70	

In addition to the online surveys, in-depth interviews lasting between 40 and 90 minutes were conducted with 10 clinical leaders and 9 patient advocates, selected to represent a broad cross-section of medical and patient expertise at a global level. The results of these interviews have been used to inform the discussion section of this paper.

Overall 19 different NETtypes have been experienced by the patients participating in the survey, the most common being pancreatic tumours, diagnosed in over 25% of the patients.

Two thirds of patients surveyed were over 50 years of age, with approximately one third being diagnosed with NETS in their 50s.

Q5: What is your age?

Answer Choices	Responses	
Under 18	0.90%	3
18-29	3.59%	12
30-39	9.28%	31
40-49	17.07%	57
50-59	30.54%	102
60-69	27.54%	92
70 and over	11.08%	37
Total		334

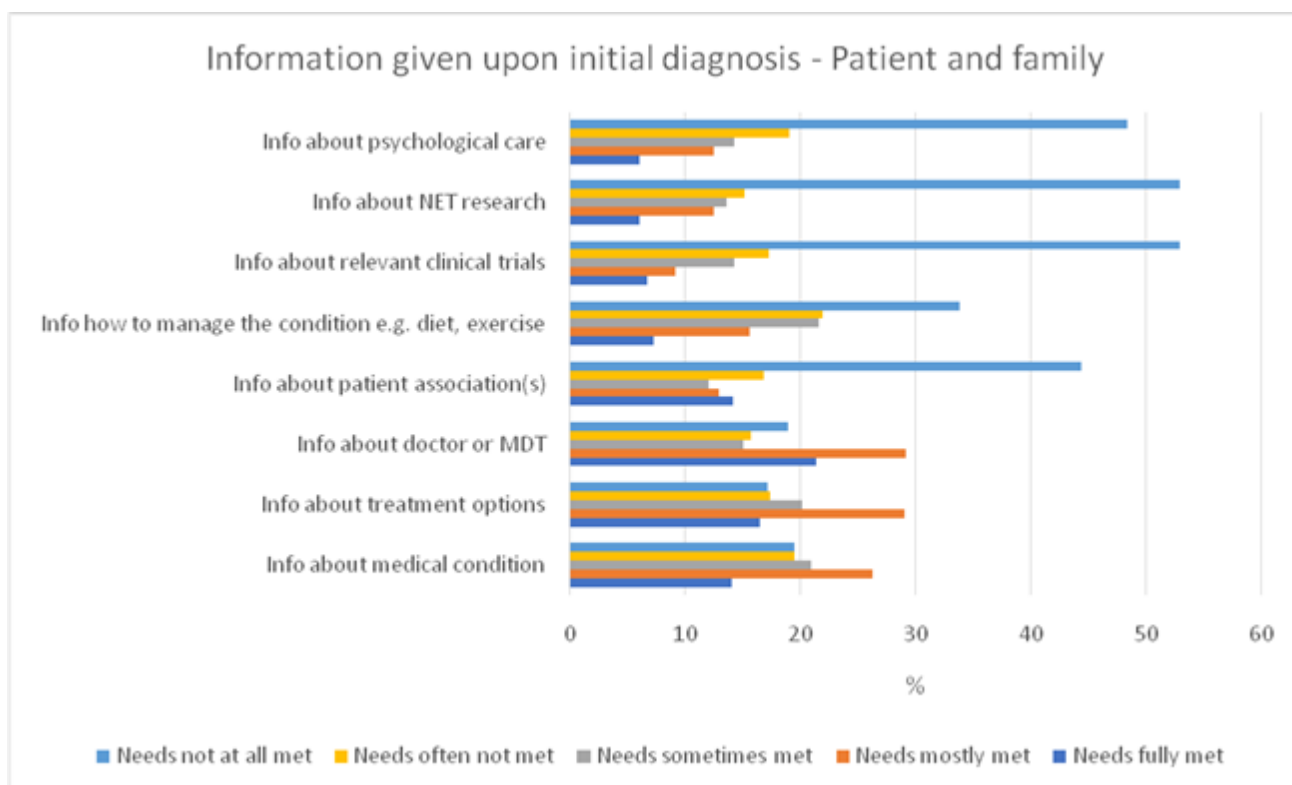
Q6: What was your age at the time of your first NET diagnosis?

Answer Choices	Responses	
Under 18	3.57%	12
18-29	7.14%	24
30-39	10.71%	36
40-49	22.92%	77
50-59	33.04%	111
60-69	19.64%	66
70 and over	2.98%	10
Total		336

RESULTS

Unmet needs in information

The comprehensiveness of information received by patients at the time of diagnosis was highly variable in terms of core information about the medical condition, treatment options, and doctor or multidisciplinary team.



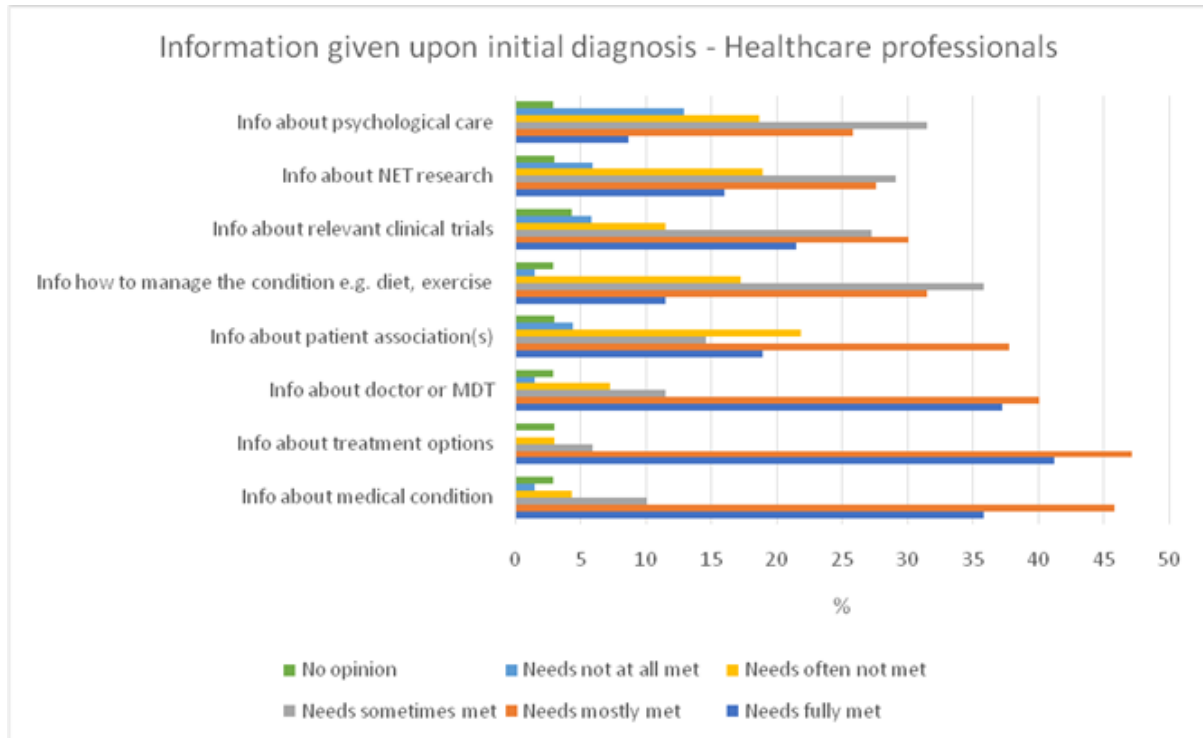
The survey highlighted several areas where patients' needs for information at the time of diagnosis are not being met:

- Information about relevant clinical trials (53%)
- Information about NETs research (53%)
- Information about psychological care (48%)
- Signposting to patient associations (44%)
- Advice on how to manage the condition e.g. diet and exercise, symptom control (34%)

In addition only 16% of respondents' indicated that their needs for information about treatment options were fully met at the time of diagnosis.

The first port of call for finding additional information was via patient association websites, with 70% of respondents using them. Sixty two percent of patients felt that their needs were mostly or fully met by these sites. Healthcare professional websites such as those of the European Neuroendocrine Tumor Society (ENETS) and North American Neuroendocrine Tumor Society (NANETS) are also widely used with 49% of respondents reporting having used them, and just over half of these finding their needs fully or mostly met through those sources.

There are clear differences in the perceptions that health professionals have about provision of information versus those of patients across all categories. For example, almost 90% of health professional respondents felt they were able to fully or mostly meet the information needs of patients about treatment options (compared with just over 36% of patients). However this is at the time of diagnosis and it can be seen that patients are more positive regarding information provided during their care overall.



In answer to the statement 'I am given all the information and explanations that I need about my condition and my treatment options':

	Needs are fully met	Needs are mostly met	Needs are sometimes met	Needs are often not met	Needs are not at all met	No opinion
Patient leader	0%	24%	38%	29%	6%	3%
Patient and family	16%	34%	26%	12%	9%	3%

Q11: How well did the information you found or requested meet your needs?

	My needs are fully met	My needs are mostly met	My needs are sometimes met	My needs are often not met	My needs are not at all met	Not applicable to me	Total	Weighted Average
Healthcare professional website (e.g. ENETS, NANETS, a hospital's website)	11.97% 34	32.04% 91	31.69% 90	5.99% 17	5.63% 16	12.68% 36	284	0.44
Healthcare professional or treating hospital – printed information	10.11% 27	17.98% 48	22.85% 61	13.86% 37	15.36% 41	19.85% 53	267	-0.08
Patient association website	19.44% 56	42.01% 121	19.79% 57	6.60% 19	2.43% 7	9.72% 28	288	0.77
Patient association - printed information	18.36% 47	30.86% 79	17.19% 44	3.13% 8	4.69% 12	25.78% 66	256	0.74

Unmet needs in standards of care

When patient leaders were asked for their views on ‘The healthcare system where I live facilitates an appropriate standard of care for patients’, 41% of respondents agreed that it mostly or fully met patients’ needs. However 23.5% answered ‘sometimes’, and over 32% of patient leaders believe that appropriate standards of care for NET patients are not met (21% stated often not met, and 12% not at all met).

Patient leaders have concerns about the support given to patients by healthcare providers in a number of important areas. The most significant being:

- 65% believe that needs for support to manage the condition through diet, exercise and symptom control are not at all met (12%) or often not met (53%)
- 76% stated that psychological care needs are either often not met (38%), or not at all met (38%)
- Treatment for diagnosed mental health conditions are often not met (44%) or not at all met (27%)

Ninety four percent of the patient leaders taking part reported that Multidisciplinary Teams (MDTs) were available in their region of interest, and 70% of health professionals said care was provided by MDTs (another 20% said it was sometimes provided). However, only 66% of patients reported having their care managed by a multidisciplinary team. For those managed by MDTs, the most common frequency of contact between a patient and the MDT is every six months.

Q14: Other than specific NET treatments, how well do you feel that patients' health is supported by healthcare providers, in terms of the following needs?

	Needs are fully met	Needs are mostly met	Needs are sometimes met	Needs are often not met	Needs are not at all met	Don't know	Total	Weighted Average
Psychological care	2.94% 1	5.88% 2	8.82% 3	38.24% 13	38.24% 13	5.88% 2	34	-1.09
Information how to manage the condition e.g. diet, exercise, symptom control	5.88% 2	11.76% 4	11.76% 4	52.94% 18	11.76% 4	5.88% 2	34	-0.56
Diagnosis of mental health conditions	2.94% 1	0.00% 0	11.76% 4	41.18% 14	35.29% 12	8.82% 3	34	-1.16
Treatment for diagnosed mental health conditions	2.94% 1	2.94% 1	8.82% 3	44.12% 15	26.47% 9	14.71% 5	34	-1.03
Support with continuing work and/or educations	3.13% 1	12.50% 4	12.50% 4	34.38% 11	25.00% 8	12.50% 4	32	-0.75
Treatment for pain	5.88% 2	41.18% 14	32.35% 11	8.82% 3	0.00% 0	11.76% 4	34	0.50
Personal care/hygiene	2.94% 1	5.88% 2	32.35% 11	29.41% 10	0.00% 0	29.41% 10	34	-0.25
Palliative care	5.88% 2	35.29% 12	17.65% 6	23.53% 8	0.00% 0	17.65% 6	34	0.29

Q19: How often are you in contact with a member of members of your multidisciplinary team?

Answer Choices	Responses
Weekly	4.08% 10
Monthly	25.31% 62
Every 3 months	22.45% 55
Every 6 months	31.84% 78
Once per year	11.02% 27
Less regularly	5.31% 13
Total	245

Of those patients under multidisciplinary team care, needs for appropriate and regular contact between patient and healthcare professional are mostly or fully met.

Respondents	Needs are fully met	Needs are mostly met	Needs are sometimes met	Needs are often not met	Needs are not at all met	No opinion
Patient leader	9%	41%	26%	15%	3%	6%
Patient and family	28%	38%	16%	8%	6%	4%
Healthcare professional	20%	53%	9%	15%	3%	0%

Only fifty percent of patients said they feel that their needs are fully or mostly met in being a true a partner alongside their medical team in decisions regarding their care.

Unmet needs in access to diagnostics and treatment

Patient access to innovative technologies is a perennial issue. The survey confirmed a belief that one of the biggest challenges in access is Gallium-68-DOTATATE/DOTATOC PET/CT scan.

Is there an appropriate diagnostic technology not available?

	Yes	No	Don't know
Patient Leader/Advocate	54%	37%	9%
Patient and family	24%	44%	32%
Healthcare professional	59%	35%	6%

For those answering "yes", the top 3 access challenges:

	1	2	3
Patient leader	Gallium-68-Dotatate PET/CT scan (85%)	FDG PET (10%)	MIBG & CT (10%)
Patient and family	Gallium-68-Dotatate PET/CT scan (73%)	FDG PET (23%)	MIBG (18%)
Healthcare professional	Gallium-68-Dotatate PET/CT scan (86%)	FDG PET (36%)	MIBG (23%)

Is there an appropriate treatment not available?

	Yes	No	Don't know
Patient leader	63%	31%	6%
Patient and family	24%	44%	32%
Healthcare professional	65%	32%	3%

For those answering "yes", the top 3 access challenges:

	1	2	3
Patient leader	PRRT (95%)	Genetic testing/precision medicine (33%)	Transplantation (10%)
Patient and family	PRRT (42%)	Genetic testing/precision medicine (25%)	Surgery (19%)
Healthcare professional	PRRT (77%)	Transplantation (44%)	Genetic testing/precision medicine (29%)

Almost half (48%) of all patients have travelled more than 300km/186 miles for treatment or consultation with a NETs specialist. Evidence shows that remoteness has an adverse impact on overall survival of NET patientsⁱⁱⁱ.

Unmet needs in research

Patients and healthcare professionals have different priorities in terms of research. “Earlier more accurate diagnosis” was the number one priority for patient leaders and patients and families, whereas for healthcare professionals it was ranked as number three. Clinical trials to improve current treatments and test new ones was the highest priority for healthcare professionals, whereas for patients and families this ranked only as fifth most important.

All groups attached a high degree of importance to research on improving quality of life, and controlling symptoms.

Each group was asked to rank the following research areas in order of priority, where 1 is most important and 7 least important to them.

Priority Research Areas	Patient Leader	Patient and Family	Healthcare professional
Basic science to understand what causes tumors to form and grow as a pathway to discovering a cure	4	2	5
Basic or translational research focused on longer survival	5	4	4
Research focused on improving quality of life; controlling/managing symptoms	3	3	2
Accurate, minimally invasive disease monitoring	7	6	6
Earlier, more accurate diagnosis	1	1	3
Clinical trials to improve current treatments, test new ones	2	5	1
Development of national and international NET patient registries	6	7	7

There is a shared view that patients are not involved enough in research design.

Are patients involved enough in research design?

	Yes	No	No opinion
Patient leader	3%	82%	15%
Patient and family	10%	53%	37%
Healthcare professional	23%	57%	20%

Each group was asked what would be their priority areas for patient involvement in research.

For patient leaders:

1. Putting NET cancer research on an equal footing with other major forms of cancer research
2. Clinical trials to improve current treatments, test new ones
3. Interpreting the results of a research initiative to ensure published results will be understood by patients

Q30:How important is patient involvement in specific aspects of research?

	Very important	Somewhat important	Not very important	Not at all important	No opinion	Total	Weighted Average
The overall strategy and direction of research funding in the field of NETs	38.24% 13	52.94% 18	8.82% 3	0.00% 0	0.00% 0	34	1.21
The design of specific research initiatives	35.29% 12	50.00% 17	14.71% 5	0.00% 0	0.00% 0	34	1.06
Interpreting the results of a research initiative to ensure published results will be understood by patients	67.65% 23	29.41% 10	2.94% 1	0.00% 0	0.00% 0	34	1.62
Setting priorities for research	45.45% 15	39.39% 13	12.12% 4	0.00% 0	3.03% 1	33	1.22
Putting NET rare cancer research on equal footing with other major forms of cancer research	73.53% 25	26.47% 9	0.00% 0	0.00% 0	0.00% 0	34	1.74
Clinical trials to improve current treatments, test new ones	73.53% 25	26.47% 9	0.00% 0	0.00% 0	0.00% 0	34	1.74

For patient and family:

1. Clinical trials to improve current treatments, test new ones
2. Putting NET cancer research on an equal footing with other major forms of cancer research
3. Interpreting the results of a research initiative to ensure published results will be understood by patients

Q31: How important is patient involvement in specific aspects of research?

	Very important	Somewhat important	Not very important	Not at all important	No opinion	Total	Weighted Average
The overall strategy and direction of research funding in the field of NETs	52.57% 174	29.91% 99	4.83% 16	2.11% 7	10.57% 35	331	1.41
The design of specific research initiatives	46.48% 152	34.56% 113	7.34% 24	0.92% 3	10.70% 35	327	1.33
Interpreting the results of a research initiative to ensure published results will be understood by patients	64.85% 214	25.45% 84	2.12% 7	0.30% 1	7.27% 24	330	1.64
Setting priorities for research	50.00% 164	34.76% 114	5.79% 19	0.61% 2	8.84% 29	328	1.40
Putting NET rare cancer research on equal footing with other major forms of cancer research	74.10% 246	18.67% 62	1.81% 6	0.00% 0	5.42% 18	332	1.75
Clinical trials to improve current treatments, test new ones	73.64% 243	20.91% 69	0.61% 2	0.00% 0	4.85% 16	330	1.76

For healthcare professionals:

1. Putting NET cancer research on an equal footing with other major forms of cancer research
2. Clinical trials to improve current treatments, test new ones
3. The overall strategy and direction of research funding in the field of NETs

Q25: How important is patient involvement in specific aspects of research?

	Very important	Somewhat important	Not very important	Not at all important	No opinion	Total	Weighted Average
The overall strategy and direction of research funding in the field of NETs	34.29% 24	55.71% 39	7.14% 5	0.00% 0	2.86% 2	70	1.21
The design of specific research initiatives	27.54% 19	52.17% 36	15.94% 11	0.00% 0	4.35% 3	69	0.95
Interpreting the results of a research initiative to ensure published results will be understood by patients	26.09% 18	49.28% 34	21.74% 15	0.00% 0	2.90% 2	69	0.82
Setting priorities for research	27.54% 19	56.52% 39	11.59% 8	0.00% 0	4.35% 3	69	1.05
Putting NET rare cancer research on an equal footing with other major forms of cancer research	49.28% 34	44.93% 31	2.90% 2	0.00% 0	2.90% 2	69	1.45
Clinical trials to improve current treatments, test new ones	36.23% 25	53.62% 37	7.25% 5	0.00% 0	2.90% 2	69	1.22

Discussion

Unmet needs in information

Good quality information that is both factually accurate and easy to understand in the local language is especially crucial for a patient who has just been diagnosed with NETs. Informed patients can take a more active role in their care. In addition, their mental and emotional health can be better supported through a greater ability to understand the condition, symptoms and the treatment options that are available, and participate in decision-making.

This survey highlighted several areas where patient needs for information at the time of diagnosis are not being met, such as relevant clinical trials, NETs research, psychological care and advice on how to manage the condition. Patients can find it difficult to access information that is credible, in their own language and relevant to their health care system. For the majority of patients, the patient support and advocacy community is filling a vital gap in the provision of that information. The survey found that most patients (62%) believe the information from patient support groups mostly or fully meets their needs. All parties should also work together to develop methods for optimally providing and ensuring that patients can understand and retain critical information about their condition and care. INCA believes government funding should be provided to support this work, in recognition of the important role the patient support groups are playing.

While the survey of healthcare professionals generally agreed with what patients shared about the areas where information is weakest, they were considerably more positive about how needs are being met at the time of diagnosis than were patients. Health professionals need to be made more aware of this difference in perception in order for them to be more sensitive to the information needs of patients at this time. The survey also indicated that health professionals could do more to refer patients to local patient organisations who can provide support.

INCA and national patient organisations in partnership with the medical community can play a valuable role in outlining which expectations are not being met at the time of diagnosis. Healthcare professionals and patient leaders can then work together to close the information gaps.

Unmet needs in standards of care

This survey found significant unmet needs in the integrated, 'wrap around' care that supports treatment. In particular this was a concern in psychological care and general lifestyle advice on diet, exercise and symptom control. Shortcomings such as these can be successfully addressed by an inclusive multi-disciplinary team (MDT).

When care is provided by an MDT, patients have reported several benefits in important aspects of their care. In a global survey of NETs patients, improvements were reported in^{iv}:

- Symptom control
- Desire to be an active partner in the care pathway
- Overall well being
- Knowledge about their condition.

The INCA survey found that MDTs are widely 'available' yet many patients are still not being treated by them, even in countries where they exist. A greater awareness of the benefit of MDT care among the key professions, especially in the "first line" specialities -- gastroenterology, oncology and pulmonology -- would be helpful to facilitate the referral pathway to MDT.

Some NET MDTs have reported progress in standards of care by the inclusion of a NETs specialist nurse who can spend more time in discussion, and is skilled in explaining difficult medical concepts to the patient. Surveys of NETs patients^v have highlighted the importance of specialist nurses for mental health and for supporting them in the care pathway. There is insufficient recognition of the value that NETs specialist nurses bring to treatment outcomes and patient-focused care. In countries where it is possible for nurses to become specialised, NETs nurses should be encouraged through the medical education system and appropriate budget to employ them in MDTs should be made available.

There is a clear opportunity for more collaboration between the MDTs and NET patient support groups. MDTs should be made aware of the activities of their local groups so that they can "signpost" them to appropriate patients. Indeed patient support groups could usefully be seen as an extension of the MDT in terms of community liaison working and referring patients between each other.

There needs to be national and global advocacy for MDTs as an essential model for delivering care to NETs patients. Progress has been made, particularly in Europe where ENETS certifies NET Centres of Excellence. To become truly embedded in treatment pathways, recognition and support for this critical concept must be included in payment and insurance systems in health care around the world. Patient pathways vary according to country and health systems. There needs to be a clear pathway established for NET, which is directed and supported by the national health system so that all patients (including those in outlying areas of a country) can reliably access specialist centre care.

Unmet needs in access to innovation

Healthcare professionals and patients are understandably eager about the availability of new treatments and those that are newly indicated for NETs. The availability of information and exchange between healthcare professionals and patients in different countries has made inequalities in access to treatment more apparent and consequently more controversial.

The survey found that one of the biggest perceived challenges in access to diagnostics is Gallium-68-DOTATATE/DOTATOC PET/CT scanning. Peptide Receptor Radionuclide Therapy (PRRT) was by far seen as the most common unmet treatment need. Unmet needs for diagnostic and imaging technology and treatments exist in all the surveyed countries, and equitable access for all NETs patients is a major challenge. In countries where progress towards appropriate availability of PRRT has been made, such as in Japan, Australia and New Zealand, patient association campaigns have been crucial.

In countries with formal Health Technology Assessment processes, patient representatives are unfortunately not routinely consulted as part of the process to determine access and funding, even though patient-reported outcomes and socioeconomic data have become more important to that picture. The assessment and approval system for innovative technologies usually calls for comparison between a new treatment or diagnostic versus the existing standard. It is a compartmentalised rather than an "all of care" approach and does not consider how decisions on care impact on the patient's quality of life. This is especially important in terms of side effects.

INCA believes that global co-operation between NETs patient organisations and medical communities may achieve greater influence, especially for the development of a compelling argument that the technology supports better and more efficient delivery of care. Patient and medical leaders need to advocate together in support of access to appropriate treatment for all.

Unmet needs in research & clinical trials

The survey found agreement on the need to involve patients more in the NETs research agenda. For patients and patient leaders the priority areas identified were:

- clinical trials to improve current treatments and test new ones,
- putting NET cancer research on an equal footing with other major forms of cancer research, and
- interpreting the results of research initiatives to ensure published results will be understood by patients.
- Health professionals added the overall strategy and direction of research funding to this list.

These findings establish a clear basis for collaboration between patient associations and the medical community to work towards an increased involvement of patients on an individual, strategic and advocacy level.

Patients have not been routinely consulted in research prioritisation and strategy, either by those awarding research grants (governments or research bodies), or by researchers. Discussions between medical professionals involved in planning and participating in research is necessarily complicated and requires specialist neuroendocrine tumour medical knowledge. However, direct patient

involvement could be facilitated by in-person consultation, especially in choosing research priorities and communication of research progress to the patient community.

In this survey, when choosing between different types of research, patients prioritised the need for research into earlier and more accurate diagnosis of NETs, followed by the need for basic research to understand and control tumours. Health professionals, on the other hand, see clinical trials as the priority, followed by research on improving quality of life and controlling symptoms, putting basic research in a lower priority. Working together to explore the reasons for these differences, and how they can be addressed in research strategies would support needs being better met. The differences and overlaps can be a rich source of exchange between these communities and forge strong alliances to define and seek support for a research agenda that can advance progress and improve the lives of patients around the globe.

Patients are keen to know about clinical trials that are relevant to them in terms of potential enrollment, and to know about new and improved treatments that may be available to them in the future. Information about clinical trials is more readily available than ever, such as in the US (clinicaltrials.gov) and European Union (EU Clinical Trials Register), but it is not easily understandable by patients.

INCA believes greater involvement of patients will yield many benefits, such as:

- Better understanding of patient priorities and their expectations from NETs research
- Consideration of how it feels to be involved in research as an individual patient – hopes, fears, impacts on their life
- Improving communication and understanding of research programs, clinical trials and their results by using lay language
- Enabling more effective advocacy on the need for funding of NETs research to potential funders: governments, non-profit organisations and individual donors
- Improving awareness of important clinical trials in the patient community, thereby increasing enrollment and ensuring that patients are well informed about treatments in development.

Collaboration between patient and clinical leaders to get patients more involved in the process of setting research priorities, and advocating for more research funding is crucial.

Summary and Next Steps

This multi-faceted assessment, although focused on the perspectives of the a sample drawn from more well-informed and engaged patients and NET clinicians, still points to major gaps in fulfilling the informational needs of patients, ensuring their access to highest standards of care and facilitating their involvement in research. For patients and clinicians not directly involved in patient groups and specialized NET centers, the gaps are most likely considerably wider.

That said, this assessment clearly points to significant opportunities for patients, advocates and clinical leaders to work together to close these gaps and improve the lives and prospects of the increasing numbers of patients diagnosed with NETs. In sum, a number of priority needs require immediate attention and coordinated actions to address them:

- ✓ the need for patient group leaders and NET caregivers to work together to "close the information gap" including providing referrals to each other to ensure that valid, reliable information is provided to patients and families in a timely fashion.
- ✓ the need to work together to secure more support (in relation to the support that more common forms of cancer receive) for NET research and to involve the patient voice in both advocacy and design of research priorities/clinical trials.
- ✓ the need to advocate together for a global standard of access to care including the latest technologies and diagnostic/treatment tools for NET patients in countries around the globe
- ✓ the need for greater collaboration across the globe to ensure patient knowledge of and participation in clinical trials
- ✓ the need to increase awareness and specialized education amongst healthcare professionals to facilitate effective diagnosis and better treatment outcomes.

- ✓ the need for greater awareness of the benefit of MDT care among the key professions, especially in the “first line” specialities, and the role of the NET nurse
- ✓ the need to secure resources/funding for patient groups to provide support and information, which can empower patients to be active partners in the treatment process.

ⁱJAMA Oncology, April 2017, "Trends in the Incidence, Prevalence, and Survival Outcomes in Patients With Neuroendocrine Tumors in the United States"

ⁱⁱ INCA Novartis Global NET Patient Survey

ⁱⁱⁱ Journal of Internal Medicine, 2017, "Clinical profile and treatment outcomes of advanced neuroendocrine tumours in rural and regional patients: a retrospective study from a regional cancer centre in North Queensland, Australia"

^{iv} INCA Novartis Global NET Patient Survey

^v INCA Novartis Global NET Patient Survey & NET Patient Foundation Patient Experience Survey