



**INSIGHTS: Patient-Doctor Relationship**  
*Survey Results*

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## **Introduction**

There may be no better way to gauge how a patient is doing with their treatment and care than to ask that person. The same holds true for how a patient perceives their relationship with the doctor or doctors who provide that care and treatment. In August of this year, the HNF set about to better understand some aspects of what we call the Patient – Doctor Relationship. Key to this was asking about different aspects of how the patient and the doctor communicated. In addition, we explored what resources patients depended upon for information about NETS. This report presents the findings of this survey.

## **Who Are The Respondents In This Survey**

As of October 2, 2015, a total of 154 people completed the most recent HNF Insights survey on the Patient – Doctor relationship. This number represents 27% of the 570 persons who were emailed the link to this survey. Those sent the email were people on the list of HNF supporters. Participation in this survey was entirely voluntary and therefore the supporters represented in the survey are self-selected.

The two findings that best reflect the self-selected nature of the sample are:

- Over 80 percent are female
- Over 90 percent are patients
- Over 90 percent are in the age range 45 years and older

We do not know the gender composition of the database used to send out the link, so we don't know how females compare to males when choosing to be a respondent. We do know that women were heavily represented in the supporter Profile Survey conducted back in May and June and now in this survey. The fact that 90+% are patients is no surprise, but this must reflect the high interest of NETS patients in trying to contribute to an understanding of the Patient-Doctor Relationship.

## **Thumbnail Sketch of Participants**

Respondents were most likely to be female, a NETS patient and Caucasian. They were likely to be age **45** or older and married. In terms of employment status, they were likely to be retired, working for wages or unable to work (25.8% say they were not able to work). The fact that over 53% have a BA degree, a professional degree or a doctorate could be responsible for driving these NET patients to seek knowledge and be more involved in the management of their own disease.

**Who completed the survey?**

Patient	91.1%
Caregiver	4.9%
Significant Other	2.4%
Other	1.6%

**Gender:**

Female	81.1%
Male	18.9%

**Age groups:**

55-64	41.1%
65-74	27.4%
45-54	21.8%
35-44	5.6%
25-34	2.4%
75 +	1.6%
18-24	0.0%

**Marital status:**

Married/Domestic partner	77.4%
Divorced	11.3%
Single	5.6%
Widowed	4.8%
Separated	0.8%

**Highest level of education:**

BA Degree	29.8%
Some college	23.4%
Professional degree	18.5%
Associate degree	12.1%
Trade/Tech training	5.6%
Doctorate	4.8%
High school	4.0%
Some high school	1.6%

**Employment:**

Working/wages	25.8%
Retired	33.9%
Unable to work	25.8%
Self-employed	10.5%
Not looking for work	3.2%
Looking for work	0.8%
Student	0.0%

**Self-described ethnicity:**

White/Caucasian	91.1%
American Indian/Native American	3.3%
Black/African American	2.4%
Hispanic/Latino	1.6%
Asian	1.6%
Other	0.0%

**The Doctors Whom Patients See**

In this survey we asked patients what type of doctor made their original diagnosis and what type of doctor were they now seeing to manage their NETS care and treatment. Respondents told us that the doctors who made their diagnosis were mainly local doctors who were NOT oncologists, but a minority of patients were diagnosed by a local oncologist or by some other type of local doctor. Less than 10% of respondents reported being diagnosed by a NETS Specialist.

**Type of doctor making NETS Dx**

Other local doctor	45.1%
Other*	26.2%
Local oncologist	13.9%
NETS specialist	9.0%
Other doctor/not local	5.7%

\* A variety of physicians and medical professionals were identified as having made the diagnosis for a patient. These included ER doctors, various types of surgeons, pulmonary doctors, endocrinologists, radiologists and various other health professionals.

### Type of doctor currently managing NETS treatment/care

When it came to managing treatment and care, the NETS Specialist was the doctor of choice, followed by a local oncologist. Other types of doctors, local or otherwise were much less likely to be involved with managing or treating respondents with NETS.

NETS specialist	43.9%
Local oncologist	32.5%
Other*	18.7%
Other local doctor	3.3%
Other doctor/not local	1.6%

\* The “Other” category included various types of surgeons, pulmonary doctors and endocrinologists.

### The Relationship Questions

One question dealt with the patient’s perception of their main cancer doctor’s knowledge about NETS and several others had to do with the way in which patients and doctors communicated with each other about the patient’s disease, treatment and care. Since these questions concerned a patient’s main cancer doctor, we expected to find that most doctors were perceived to be knowledgeable about this cancer.

#### Physician Knowledge (Question 6) -- **In your opinion, how knowledgeable is your main cancer doctor about your Neuroendocrine Cancer? Use a scale of 1 though 10**

It is encouraging that 60% of the respondents to this question perceived their doctor to be knowledgeable about their cancer (gave a score of 8 or higher). Slightly more than One-Third said their doctor was at the top (10) of the scale.

On the other hand, slightly more than One-Third indicated their main doctor was perceived to be not very knowledgeable (a score of 7 or less). One-Fifth of respondents scored their doctor a 5 or less. The conclusion --- the doctors who treat some 40% of the respondents, need to be better educated and informed about the diagnostics, treatment and care of patients with NETS.

Knows very little:	1	<b>7</b>	5.8%
	2	<b>5</b>	4.2%
	3	<b>9</b>	7.5%
	4	<b>3</b>	2.5%

	5	<b>6</b>	5%
	6	<b>11</b>	9.2%
	7	<b>6</b>	5%
	8	<b>16</b>	13.3%
	9	<b>13</b>	10.8%
Knows very much:	10	<b>44</b>	36.7%

Score 1 – 5 = 20%  
 Score 6 -7 = 14.2%  
 Score 8-10 = 60.8%

The respondents to this question were asked to tell why they gave their score. Below are some typical verbatim explanations for the score ranges.

**Range 1-5 (Knows Very Little)**

- Doctor hurries me through and offers no treatment options. Treats me as if I'm a hypochondriac
- He admits he has never treated it
- He is considered a carcinoid specialist yet will not test me as necessary and had told me I am cured.
- He has given me very little information on this disease

**Range 6-7 (Somewhat knowledgeable)**

- Doesn't think removing the primary is a big deal or even finding it
- My oncologist deals with other types of cancer and is not a NET Specialist
- I think he knows a lot about NETS, but very little about patient care

**Range 8-10 (Very Knowledgeable)**

- He is always up to date o the latest information, tests, trials, etc.
- Because she has given me options for my treatment now and down the road...
- He has been treating NETS for years
- He is very experienced with a proven research track record

**Communications- Listening (Question 8) When you see the doctor who oversees your cancer care, to what degree does he/she listen to your questions?**

Listening is a key prerequisite for a successful patient-doctor relationship. A patient always wants their doctor to listen to them when they are telling the doctor about their medical problems and concerns. While there are often many posts on forums and Facebook sites about how doctors never listen to their patients, this was not the case in this survey. Over Three-Quarters of respondents (a score of 8-10) said their doctor listened to them. At the same time, nearly One-Fifth of respondents gave their doctor a score of five or less, meaning that in the eyes of the respondent, the doctor did not much listen to what the patient was telling them. This indicates that some doctors need to learn how and when to listen to their patients.

**Does Not Listen**

1	3	2.5%
2	5	4.2%
3	2	1.7%
4	5	4.2%
5	8	6.7%
6	4	3.4%
7	3	2.5%
8	9	7.6%
9	15	12.6%
10	65	54.6%

**Always listens**

Score 1 – 5	= 19.5%
Score 6 -7	= 5.9%
Score 8-10	= 76.8%

Respondents to this question were asked to tell why they gave their score. Below are some typical verbatim explanations for the score ranges.

Range 1-5 (Does Not Listen)

- If I ever have a concern, it is dismissed quickly. Kind of makes me feel I am crazy for asking...
- He forgets to order imaging and tests we discuss at the visit
- She is not rude most of the time and humors me, but doesn't show any genuine concern
- Belittles me when I talk/ask about most current treatment available.
- He spends little time with us and doesn't encourage questions

Range 6-7 (Listens Sometimes)

- Spends little time with me. Fast answers. Difficult to keep up
- He doesn't appear to hear my comments or questions at times...

Range 8 – 10 (Always Listens)

- My questions are answered to the best of his ability...there is much uncertainty...
- Always listens to my questions and takes the time to answer them
- He and I make educated decisions together in consultation with others...
- He never rushes and appointment and listens carefully and answers

**Communications - Answering Questions (Question 10) When you see the doctor who oversees your cancer care, in your opinion, to what degree does he/she answer your questions?**

Answering a patient's questions about their care or treatment is another prerequisite to a successful patient to doctor relationship. A patient always wants their doctor to answer questions about their situation, if the doctor has the information. Just like "listening", there are many posts on forums and Facebook sites about how patients do not get answers from doctors or they get answers that are hard to understand. Unlike the question on listening, only Two Thirds of respondents gave their doctor a score of 8-10 for trying to answer all of their questions. Nearly One Third of respondents put their doctor's efforts at a 7 or less. These results indicate that this is another area where improvement in a doctor's knowledge of NETS would strengthen the patient-doctor relationship.

Does Not Answer My Questions

<b>1</b>	<b>4</b>	3.4%
<b>2</b>	<b>4</b>	3.4%
<b>3</b>	<b>4</b>	3.4%
<b>4</b>	<b>3</b>	2.6%
<b>5</b>	<b>8</b>	6.8%



6	<b>9</b>	7.7%
7	<b>8</b>	6.8%
8	<b>11</b>	9.4%
9	<b>10</b>	8.5%
10	<b>56</b>	47.95%

**Tries to Answer All of My Questions**

1 – 5	=	19.6%
6 -7	=	14.5%
8-10	=	65.8%

The respondents to this question were asked to tell why they gave their score. Below are some typical verbatim explanations for the score ranges.

**Range 1-5 (Does Not Answer My Questions)**

- I don't ask many questions. Pretty intimidated
- He answers to the best of his ability, but that isn't saying much
- Last appointment with doctor, he did not let me ask questions

**Range 6-7 (Somewhat Answers Questions)**

- I never get a good answer when I ask what my prognosis is.
- Answers only to what he knows
- He answers, but tells me it is slow growing, so we don't have to do anything for years.

**Range 8 – 10 (Tries To Answer My Questions)**

- Does a very good job of answering
- He is knowledgeable about the disease and tests and treatments
- Because he is open to input from other doctors for answers he does not know
- He is extremely knowledgeable and wants me to feel comfortable.

**Communications – Asking Questions (Question 14) - In your opinion, how easy or hard does your main cancer doctor make it for you to ask questions about your case? [1 to 5 scale]**

The ability of a doctor to listen to their patient and answer questions from that patient are much desired traits by patients, but some doctors can be more difficult to talk to than others. Often it is the personality of the doctor that determines how easy or hard it is for a patient to actually ask questions. Most patients seem to know when it is easy or hard for them to ask questions or communicate with the doctor. So, the receptivity of the doctor to be open to

questions is another key trait that affects the success of the patient-doctor relationship.

The best score on this question was a 5, yet only slightly over 60% of respondents said it was very easy to ask questions of their doctor about their case. This means that 40% of respondents did not find it easy to ask questions of their main doctor. Clearly, some doctors need to understand how their demeanor, receptivity to answering questions and knowledge affects their relationship with a patient.

Very Hard:

1	<b>8</b>	6.9%
2	<b>7</b>	6%
3	<b>17</b>	14.7%
4	<b>13</b>	11.2%
5	<b>71</b>	61.2%

Very Easy

3 or Less =	26.6%
4 =	11.2%
5 =	61.2%

The respondents to this question were asked to tell why they gave their score. Below are some typical verbatim explanations for the score ranges.

Range 1-4 (Very Hard)

- \* Because of errors made in the past regarding treatment plans
- \* Because he is rather off-hand
- \* Feel like I really shouldn't be concerned. Therefore I don't ask. I just do as I'm told.
- \* I don't feel confident that I can trust his facts or perceptions

Range 5 (Very Easy)

- He does not show ego. Gives me the choice in my treatment
- Her body language as well as what she says tells me that I can ask her anything and I do
- I think he knows his stuff and keeps up with latest developments around the world.
- No question goes unanswered

## Communications – Patient Confidence (Question 12) - **How confident are you in asking your main cancer doctor questions about your case?**

Of all the questions dealing with the patient-doctor relationship, the answer to this question is probably the most important. In order to have two-way communications that work, the patient must have a high level of confidence that the doctor is going to be open to discussing the details of their case. Slightly less than 60% of all respondents reported they had a high level of confidence for asking their main cancer doctor about their case.

Some 40% of respondents did not have a high level of confidence to ask questions of their doctor. The responses to this question indicate that work must be done with patients to encourage them to communicate with their doctor and that work must be done to educate/inform doctors about the best ways to communicate with their patients during the time the patient is with them. Again, this reflects on the issue of doctor demeanor and receptivity to making the relationship with the patient a two-way street.

### Not very confident

1	<b>13</b>	11.2%
2	<b>7</b>	6%
3	<b>14</b>	12.1%
4	<b>14</b>	12.1%
5	<b>68</b>	58.6%

### Very confident

3 or Less = 29.3 %

4 = 12.1%

5 = 58.6%

The respondents to this question were asked to tell why they gave their score. Below are some typical verbatim explanations for the score ranges.

### Range 1-3 (Not Very Confident)

- She is ready to dismiss me about as soon as she walks through the door
- I don't mind asking questions but usually I'm better off seeking answers on my own.

- He believes I am cured and shouldn't have too many questions
- I only get to see him for 15 minutes and he types on his laptop the entire time

**Score 4 (Somewhat Confident)**

- He gives me opportunities to ask what I want to know
- She lets me ask questions, but doesn't always answer
- I can email or call any time.

**Score 5 (Very Confident)**

- Always open to questions
- Approachable doctor with open attitude and allows adequate time in appointment.
- He always tells me to ask him questions or concerns
- She is always want to put me at ease and answer any question I have

**Patients Seeking Information**

There was a time when patients always did what the doctor ordered. In today's world, the doctor as the source of all medical information is changing. The advent of the Internet and the publication of online medical resources have changed the doctor-patient relationship forever. The doctor continues to be the central resource for delivering treatment and care, but our findings indicate that the doctor may no longer be the repository for all medical information in the eyes of the patient.

In today's world a patient can find an almost never-ending supply of information about diagnostics, treatment and care. This does not mean that the patient can understand the information or that the information can be considered trustworthy and reliable, but the fact remains that the patient can become better informed and can potentially better understand their own health situation through the use of the Internet.

All long-time NETS patients know that all patients are not created equal. This is true relative to the nature of NETS and to patient responses to treatments. It is also true when it comes to patients seeking information and knowledge about their cancer and treatment options. Some seek more information and others do not. It is a personal choice.

Possibly one factor that could influence a patient's interest in being better informed about the cancer and treatment options, is the attitude of the doctor toward a patient seeking such information. We asked respondents to tell us their doctor's attitude on this topic.

Doctor encouraged patient to look for information	47%
Doctor not concerned either way	39%
Other	14%
Doctor discouraged patient to look for information	1%

The positive outcome of these responses is that doctors are not discouraging patients from seeking information about their cancer. The downside to these responses is that less than half of the respondents were being encouraged and nearly 40% thought their doctor did not care whether they looked for information or not.

Perhaps doctors will need to consider how to guide their patients to seek valid information and in the long run improve outcomes for patients and reduce their own workload through the self-education of their patient. In today's changing world of medical research information online, it is unrealistic to think that doctors can keep up with all that is available --- relative to new and developing treatment options. The doctor may need to see the patient as more of a partner in their care rather than simply a recipient of care.

**Patient Use of the Internet as a Resource for NETS information**

The purpose of asking this question was to gain insight to patient/caregiver use of the Internet for obtaining information about NETS. The conventional wisdom would have us believe that primarily younger people (Age 40 and younger) are the more active users of the Internet. The respondents to this survey indicate that patients and caregivers frequently use the Internet as a resource to understand their Neuroendocrine cancer.

Nearly 80% of respondents reported frequently using the Internet to seek information about NETS. It is likely that future communications from The Healing NET may need to use various Internet channels to interact with and inform its supporters. The same is likely to be true of doctors when they communicate with their patients.

**Internet as a Resource (Question 17) When it comes to seeking information on NETS related to diagnosis and treatment, how would you describe your use of the Internet as a resource?**

Seldom Use Internet:

1	1	0.9%
2	1	0.9%

3	7	6%
4	16	13.8%
5	91	78.4%

Frequently Use Internet:

**5 = 78.4%**

1-3	6.8%	Seldom use
4	13.8%	Sometimes use
5	78.4%	Frequently use

The respondents to this question were asked to tell why they gave their score. Below are some typical verbatim explanations for the score ranges.

#### Range 1-3 (Seldom Use)

- I used it more when I was first diagnosed. Not so much now
- I rely more on info I get from fellow NETS patients, support group and ACOR
- I get enough information and I can ask the NET nurse

#### Score 4 (Sometimes Use)

- I am always doing research on the Internet and asking questions
- I follow blogs and support foundation to hear what others are doing
- I mostly use the Internet for information from other patients on drug side effects and managing symptoms.

#### Score 5 (Frequently Use)

- Always research and follow groups (Facebook, ACOR, others)
- Docs do not help. NET docs online do help.
- I am constantly reading posts, looking at videos from conferences to stay informed and help guide my local doctor.
- I joined ACOR and follow many net blogs
- The Facebook groups, Google and NET websites have been very helpful.

## **Most Important Resources Used**

For those respondents who said they sought information about NETS, the resource they depended on FIRST was:

Doctor	37%
Websites on NETS	35%
Online Forums	16%
Other sources	6.3%
Local support grp	2.8%
Known Medical orgs	2.1%
Health-related Foundations	0.7%

The number TWO choice of resource looked like this:

Websites on NETS	31.2%
Doctor	23.4%
Online Forums	21.3%
Local support grp	7.8%
Other sources	7.1%
Known Medical orgs	3.5%
Health-related Foundations	2.8%

Note that each respondent was asked to give their first choice and then in the next question they were asked their second choice. These were fixed choices on the survey and you could only give one response to each question. This means that each answer represented a separate group. By digging deeper into the data it was found that the respondents who gave a first choice identified three main resources. The second choice they identified were the same three, but in a different order.

- Those selecting Doctor as #1, gave Websites or Online Forums as #2
- Those selecting Websites as #1, gave Online Forums as #2
- Those selecting Online Forums as #1, gave Doctor as #2

The real eye-opener for the answers to these questions is the role of Internet-based resources in providing information about NETS.

When you look at the numbers you see that for first choice the combination of “Websites on NETS” and “Online Forums” account for 51% of responders who say these are their FIRST choice. This is compared to doctors who were only the first choice of 37% of the participants.

This comparison holds true for responders who identified their Second choice. In this case 52.5% of responders said that “Websites on NETS” and “Online Forums” were their second

choice. Compare this to the 23.4% who said the doctor was the Second choice.

The fact that the self-selected respondent base is 80% women and 74% of them are in an age range of “45 and older” seems to be quite impressive. Recent stats show women using the Internet in higher numbers — even more so among women in the 20-30 age range, but not necessarily in the 45+ age range. Our findings probably indicate a high interest among women (especially patients) to use Internet resources when it comes to the subject of their cancer care.

There is another take-away from the responses to these questions. The results do not signify that the doctor is becoming less relevant to patients, but they do imply that patient **accessibility** to NETS information is a significant factor in terms of where patients now look for this information.