PAN Foundation

CONSIDERING THE WHOLE PATIENT: REPORT ON PATIENT CONCERNS REGARDING SOCIAL DETERMINANTS OF HEALTH

APRIL 2021

Contents

Executive summary

Social determinants of health are the conditions in which people are born, grow, live, and work that shape their health, like housing and socioeconomic status.[1] Economic stability, education, healthcare access and quality, neighborhood and environment, and social and community context drive more than 80 percent of health outcomes.[2] Leaving social factors unaddressed can lead to problems adhering to treatment and poor health outcomes. Conversely, addressing social determinants has the potential to improve patient health outcomes and reduce avoidable healthcare spending.

The following report details the methods and results of a survey created and administered by the Patient Access Network (PAN) Foundation, investigating the level of concern PAN patients have about key social determinants. After reviewing the results, it will be clear that patient support organizations must screen patients for social determinants of health to ensure that their needs are being met. To support this effort, PAN has provided a survey that organizations can use in whole or in part as a screening tool.

Background

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic, and rare diseases with the out-of-pocket costs for their prescribed medications. We offer nearly 70 disease-specific assistance programs.

As one of the nation's largest charitable organizations helping the underinsured, we know all too well the plight of patients with high out-of-pocket prescription costs. To date, we've served nearly 1 million patients, about half of whom are living on less than $26,000 a year—under 200% of the Federal Poverty Level.

We also partner with leading, national nonprofit organizations that are subject matter experts in a specific disease or condition. Through our referral program, patients who come to PAN for financial assistance can receive holistic follow-up, including educational and support services that can help address their specific needs and concerns.

Our goal is to better support our patients, which includes considering the impact of social determinants of health. As part of that process, we created a patient survey to assess their most pressing concerns in six targeted areas.

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1.   Artiga, Samantha and Hinton, Elizabeth. Beyond HealthCare: The Role of Social Determinants in Promoting Health and Health Equity. Kaiser Family Foundation. May 10, 2018. https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/.

2.   Magnan S. Social Determinants of Health 101 for Health Care: Five Plus Five. National Academy of Medicine. 2017. https://doi.org/10.31478/201710c.

Purpose of survey

Patients seek assistance from the PAN Foundation because they have challenges paying for their prescription medications. We wanted to understand what additional factors and concerns patients face in order to design programs and services that better meet their needs.

The PAN Foundation distributed this survey on social determinants of health to:

- Learn more about patient concerns and barriers to medication adherence and healthcare services.
- Better address those concerns in future assistance programs.
- Share specific patient needs with our patient support and advocacy partners so they can provide tailored educational and support services.

Unfortunately, it is common for people who need support to underreport their concerns.[3] Therefore, phrasing the screening questions to get accurate responses was a priority. Patients may change their answers based on how a question is worded, so part of the purpose of the survey was to determine which questions ensured consistent responses to identify social determinant of health concerns so our partners will be able to use this survey as a tool to better serve their patient communities.

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3.   Johnston DW, Propper C, Shields MA. Comparing subjective and objective measures of health: Evidence from hypertension for the income/health gradient. Journal of Health Economics. 2009, 28(3): 540–552.

Overview of findings

The PAN Foundation surveyed about 7,500 patients receiving co-pay and premium assistance grants. Among the people surveyed, 78 percent were over the age of 65, and all were living with at least one serious illness.

Because the goal was to better understand which social determinants are most concerning to patients, the survey focused on six factors: daily activities, food, healthcare services, housing and utilities, social support networks, and transportation.

The biggest concern for most patients was financial support for healthcare services. More than 70 percent of patients surveyed also reported challenges paying for basic needs, like food, housing, visiting the doctor, transportation, or heating. Other key takeaways included:

- Patients need help maintaining their long-term social and physical needs.
- Access and affordability were of equal concern to patients who reported issues with transportation.
- Patients reported food security concerns at double the national average.

Based on these results, we created a survey tool with strategic screening questions that we will incorporate into PAN's grant enrollment process. The results will help us continually evaluate the social determinants of health that are impacting the patients we serve. We believe that understanding social determinants of health is critical for patient support and improving treatment adherence, so we are also making this new tool available to all patient support organizations. Incorporating even a few screening questions can help organizations better understand and assist their patient communities.
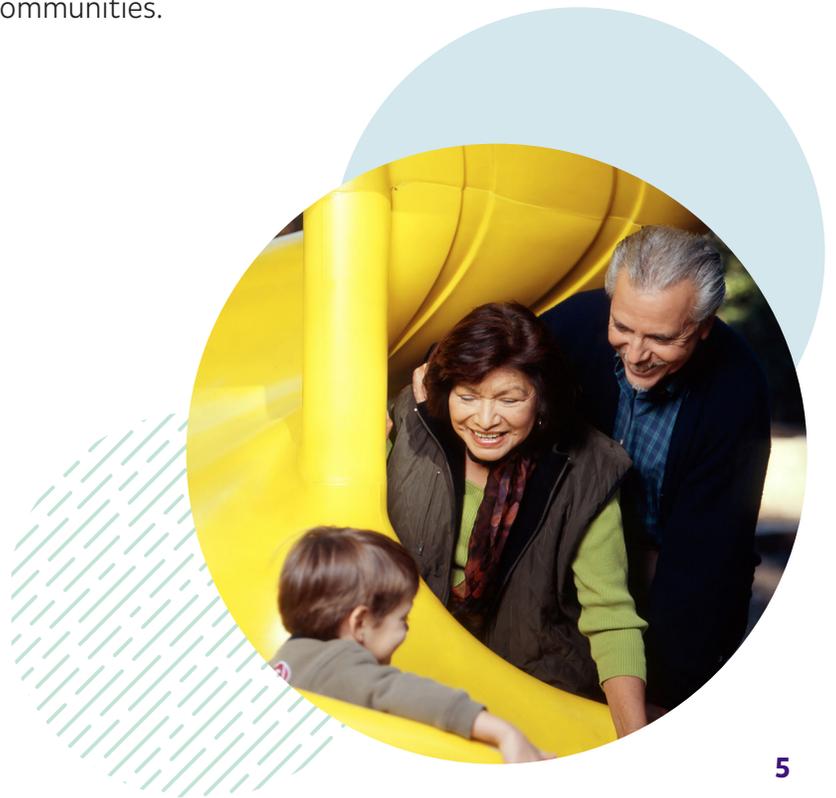
Methodology

The survey included 32 multiple choice questions. The first five questions captured the patients' demographics: age, gender, education, zip code, and the health condition(s) for which they are receiving assistance through PAN. The sixth question was the primary screener, narrowing the patients down to those with concerns about social determinants of health. Based on their answer to question six, patients either proceeded to the rest of the survey, or exited. [4]

Survey Logic
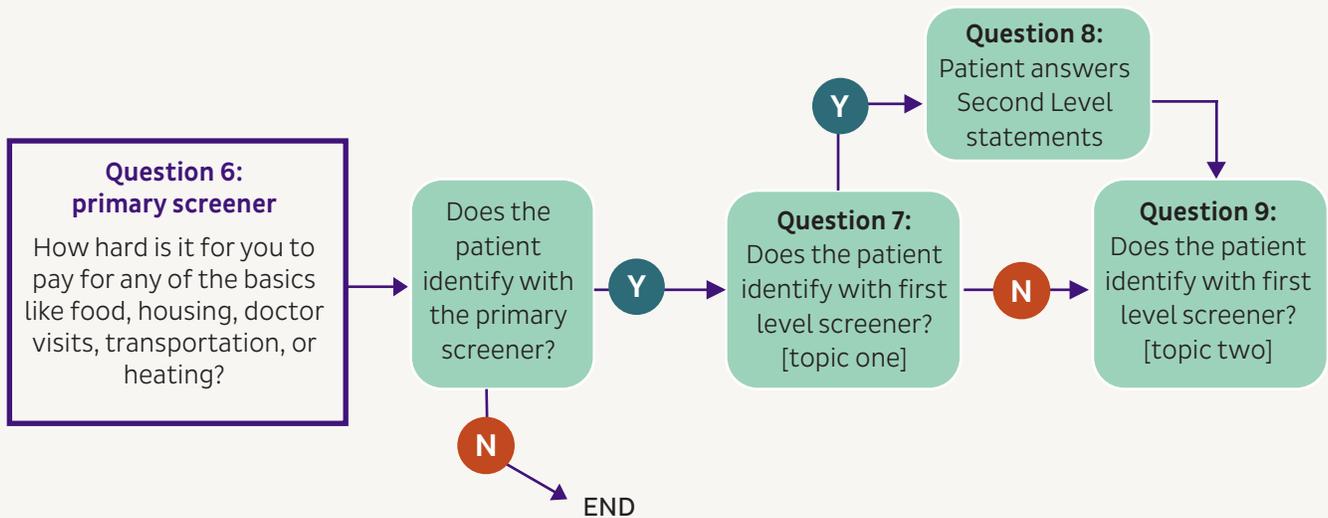
This logic continued through the survey. Patients who responded affirmatively to the first-level screening question, indicating challenges paying for basic necessities including food, housing, doctor visits, transportation, or heating, were then asked to respond to a second-level statement relating to a specific social determinant of health.

There were 12 first-level screening questions in the survey, addressing each of the six social determinants twice. Every first-level question was unique, but there were only six distinct second-level statements, one per social determinant. In some of these second-level statements, patients were able to select more than one response from a list. The second-level statements were the same for both applicable questions. This progression was created to see (1) if patients responded "yes" to both first-level screening questions, and (2) if they selected "yes," that their follow-up responses matched.

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4.   The primary survey screening question asked patients how hard it is to pay for the basics of food, housing, doctor visits, transportation, or heating (i.e. the social determinant of health). If patients indicated "not hard at all," then the survey concluded. If patients indicated "somewhat hard" or "very hard," then they went on to the next question. 72 percent of patients (n=5,463) indicated that it was "somewhat hard" or "very hard."

Distribution

The survey was distributed by email to PAN patients who were receiving co-pay and premium assistance grants (n=35,456) as of August 24, 2020. The survey was open for two weeks and received 7,558 responses.[5] All survey participants were living with cancer, or a chronic or rare disease.

Findings

Of the 7,558 total patients who responded to the survey, 78 percent (n=5,923) were over the age of 65. Most of these older adults are on Medicare and represent the group that primarily benefits from and has access to PAN's assistance programs. Every person receiving assistance through PAN is living with a serious illness, like asthma, heart failure, or cancer and about half of PAN's grant recipients are living on less than $26,000 a year.

Patients find it difficult to pay for their basic needs.

In response to the primary screener question—question number six noted above 72% of patients indicated that it was "very hard" or "somewhat hard" to pay for their basic needs, such as food, housing, doctor's visits, transportation, and heating. This group of patients continued through the survey, while those who said they did not have concerns paying for basic needs exited the survey.[6]

The majority of patients are concerned about financial support for healthcare services.

Across all first-level screening questions—the questions introducing each social determinant—the largest number of patients selected "yes" (49 percent, n=3,479) to questions related to healthcare services. This indicated that patients were most concerned with this social determinant, likely because it is closest to PAN's mission, and therefore most impacts the audience of the survey. Patients who replied "yes" to the first-level screener questions were then prompted to respond to a second-level statement.

In their responses, patients indicated they have equal concerns about paying bills from the doctor and the dentist. This is not unexpected given that the patients surveyed were all receiving charitable assistance for healthcare expenses. While there was some variation in answers for other social determinants based on how questions were worded, questions about financial support for healthcare received consistent "yes" answers across the first- and second-level questions. This high rate of affirmative responses indicated a significant concern.

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5.   PAN received 153 responses from patients who completed the first five questions and dropped out before replying to question six. For the purposes of survey analysis, these 153 responses have been excluded from the data and from this report.

6.   Of these 5,463 patients, 39 percent (n=2,129) dropped out after this initial screener question.

Food security concerns exceed the national average.

Nearly 10.5 percent (13.7 million) of U.S. households were food insecure at some time during 2019, [7] meaning that at some point they did not have enough food for all household members. Among Medicare beneficiaries 65 years or older, 9.1 percent reported food insecurity, just shy of the national average for all households.

We expected a similar percentage in our response rate. What we actually learned was that patients reported more than double the rate of food insecurity, indicating that it was a significant concern.

- I have limited or uncertain access to enough food or to nutritious food. *(27 percent, n=1,491)*

- I am concerned about having enough food. *(22 percent, n=1,105)*

Few people who struggle with food insecurity wish to be identified due to stigmas perceived with the lack of access to food.[8] This stigma has become especially concerning during the COVID-19 pandemic where increasing numbers of Americans are becoming food insecure.[9] That such a large number of PAN patients admitted concerns with this topic further indicates the gravity of the situation and this determinant in particular.

Also of note is that questions on food insecurity received a lower rate of affirmative answers than other social determinants in the survey. While the percentage of PAN patients with concerns exceeded the national average and Medicare average, other social determinants were still of greater concern to a larger population.

Patients need help maintaining their long-term social and physical needs.

Patients who identified gaps in their social support networks were given a list of second-level statements to evaluate. They were able to select multiple statements if more than one applied. These statements focused on either:

- Periodic social support (Help in case of emergency; someone to check in occasionally), and/or

- Long-term social support (I spend most of my time alone, but I would rather socialize with other people more often).

7.   USA Economic Research Service, US Department of Agriculture. https://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us/key-statistics-graphics.aspx/.

8.   David, Elena. Food Insecurity in America: Putting Dignity and Respect at the Forefront of Food Aid. Retrieved Jan 28, 2021. https://www.socialconnectedness.org/wp-content/uploads/2018/02/Food-Insecurity-in-America-Putting-Dignity-and-Respect-at-the-Forefront-of-Food-Aid.pdf.

9.   Strochlic, Nina. One in Six Americans Could go Hungry in 2020 as Pandemic Persists, National Geographic. Retrieved Jan 28, 2021. https://www.nationalgeographic.com/history/2020/11/one-in-six-could-go-hungry-2020-as-covid-19-persists/.

Table 1. Social support networks: second-level screeners	Yes to both screeners	No to 1st screener; yes to 2nd screener	Yes to 1st screener; no to 2nd screener
I spend most of my time alone, but I would rather socialize with other people more often.	88% n=864	81% n=686	82% n=534
I don't have anyone to help me in case of emergency.	20% n=198	10% n=85	6% n=42
I need someone to check in on me from time to time.	26% n=251	21% n=179	16% n=131

(Note: patients were able to select multiple answers, so results do not add up to 100%)

Results showed that long-term social support was a more significant concern to patients, indicating that they either have assistance in the short-term, or that long-term support is a more pressing concern for them to address.

Patients who indicated a need for support in daily activities were shown two second-level statements. Patients were able to select both statements if applicable. Statements described needs for:

- Personal care (eating, bathing, dressing, walking, using the toilet), and/or
- Physical support (shopping, preparing food, housekeeping, laundry, finances, or managing medications).

Table 2. Daily activities: second-level screeners	Yes to both screeners	No to 1st screener; yes to 2nd screener	Yes to 1st screener; no to 2nd screener
I need help with eating, bathing, dressing, walking, or using the toilet.	34% n=381	27% n=55	7% n=95
I need help with shopping, preparing food, housekeeping, laundry, finances, or managing my medications.	91% n=1,017	90% n=181	95% n=1,206

(Note: patients were able to select multiple answers, so results do not add up to 100%)

Patients showed little variance in their responses to this determinant. This is possibly because they already had support from other caregivers or insurance-provided resources to account for physical needs. Further, this indicated that personal care support, while important, was far less critical than long-term physical support for daily activities.

Patients are equally concerned with transportation access and affordability.

Of all the social determinants, transportation received the most "no" responses when patients were asked both first-level screening questions (n=4,010, 80 percent of all patients). While transportation was the least concerning social determinant for patients surveyed, it should not be downplayed that one in five patients still had concerns about their access to transportation.

Of all the second-level statements, patients showed the greatest uniformity in responses for those related to transportation. If patients indicated concern about this social determinant, they were then asked if they struggled with access to transportation or affordability of transportation. Patient responses indicated a similar level of concern about access to and affordability of transportation.

Patients seem more likely to report general concern than personal difficulty or a need for help.

While many patients noted significant concerns about various social determinants, responses indicated that they were less likely to answer affirmatively when asked questions directly. Patients were more likely to report concerns when the question indicated an indirect issue or general concern with the social determinant. Patients may be more willing to acknowledge their concern for an issue rather than their lack of access to that social determinant.

There can be stigma associated with financial challenges to afford necessities. These responses may also imply patients are acknowledging concerns that are temporary. Patients might indicate a concern at the time of the survey but may not consider it a long-term difficulty or barrier to their healthcare.

Table 3. *Responses to direct vs. indirect questions*

Daily activities		Healthcare services		Housing and utilities	
Direct statement	*Indirect statement*	*Direct statement*	*Indirect statement*	*Direct statement*	*Indirect statement*
I need help with basic day-to-day activities.	**I am concerned** about being able to do basic activities that allow me to live independently.	**I have difficulty** paying for health care services other than prescription medications.	**I am concerned** about paying for visits to the doctor or dentist.	**I have difficulty** with housing, paying rent or mortgage, or paying for my phone or utility bills.	**I am concerned** about the cost of housing and utilities.
28%, n= 1,494	51%, n= 2,931	57%, n= 3,313	65%, n= 3,553	39%, n= 2,351	67%, n= 3,684

Recommendations for patient support organizations

After reviewing and analyzing the survey results, we have considered recommendations specific to the survey screening questions as well as ways in which we can begin to address patient inequities with our partners. The PAN Foundation developed this set of social determinant screening questions that can be used by a variety of organizations to identify patients who are experiencing barriers to their healthcare. We plan to integrate the social determinants of health screening in our patient enrollment process for financial assistance programs at PAN in the coming year. Our hope is to share those results with alliance partners so they can have more tailored conversations and better understand patient concerns and resources required to address those concerns. We are also making these questions available as a tool for other organizations to use in 2021.

Based on our findings and analysis, other recommendations are to:

1   **Use screening questions to identify concerns about social determinants of health, regardless of resource constraints.**

It is fundamental for patient support organizations, patient advocacy groups, and healthcare providers to screen patients for concerns and barriers related to social determinants. Many resources and directories already exist that are available to address patient need across various social determinants. We suggest reviewing:

- **Benefits Checkup**, listed under the National Council on Aging, provides a website directory to seniors and Medicare beneficiaries.
- **Find Help**, formerly known as Aunt Bertha, is the largest and most widely used social care network in the country, assisting people in need of various social services and referrals.
- **United Way** provides referrals primarily through its 2-1-1 hotline, either through text or phone call. United Way also has a web-based directory.
- **One Degree** is a social care network that is used by both help-seekers and by the people who support them (case managers and social workers).

Organizations do not need to invest significant resources to provide patients with this information. They can begin to integrate the screening questions and findings from the PAN survey into conversations with patients directly. While patients are mostly interested in financial support, there are other ways to assist them too. But connecting patients with resources and organizations that provide the support they need can only happen after screening occurs.

Organizations can choose screening questions that address a broad scope of social determinants or focus on the needs of a specific population. Certain social determinants may impact patients differently, and organizations can choose to screen for social determinants that are most relevant to their unique patient communities.[10] For example, our findings indicated that patients with conditions impacting physical mobility reported higher concerns with social support networks and daily activities. For patients experiencing financial concerns paying for their medications, our survey indicated that the following determinants affected medication adherence the most (in descending order):

1. Healthcare services
2. Housing and utilities
3. Daily activities
4. Social support networks
5. Food
6. Transportation

2 **Determine whether to focus providing your patients with financial or non-financial assistance**.

The older adults we surveyed considered financial support for healthcare services as the answer to their most pressing concern: paying for their doctor's bills and dental care. Any organization looking to screen patients with serious illnesses will best serve the maximum number of patients by screening for this social determinant first. As patients report their concerns, it is important to distinguish between financial and non-financial concerns and understand how best equipped your organization is to address either type. It's useful to focus on either patient referrals or financial support services, depending on the capabilities of the organization.

For patients who have identified a need for financial assistance with out-of-pocket healthcare costs and related support services, we recommend **FundFinder**, which tracks open assistance funds and support groups in one place. Patients can sign up to receive a text or email alert when funding is available, and the support directory is always listed.

3 **Use screening questions to determine patient needs and referral recommendations.**

Patient support does not need to be financial to be meaningful. Many of the patients surveyed lacked access to robust social support networks and lacked support to successfully perform even the most basic daily activities. For many patients, this support is urgently needed. PAN and its partners can help patients find local resources that can address their concerns and provide information to patients seeking educational assistance. After asking a few screening questions about social determinants of health, organizations can quickly identify gaps and provide customized referrals to patients.

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10.   For example, organizations working with the multiple sclerosis patient community will find that these patients are more impacted by the Daily Activities screener question than organizations working with other patients.

Conclusion

Based on these survey results, we are certain that there is more work to be done to support the patients we serve and that older adults living with serious illness and limited income have significant concerns. This survey is not inclusive of every social determinant that could be considered, and it does not begin to address the root cause of these concerns, but it is a start. In addition to expanding our enrollment process to include screening questions focused on social determinants of health, we plan to track our patient data to inform the design of future assistance programs.

We are proud to share this screening tool with our colleagues in the patient support community. Accounting for social determinants of health is simply too important not to share this valuable resource.

Contact

If you or your organization have questions about this report or using this screening tool, please contact Ayesha Azam, Vice President of Medical Affairs at the PAN Foundation, at **aazam@panfoundation.org**.

PAN Foundation

Appendix A: All responses to survey question six, by disease fund

Q6: How hard is it for you to pay for any of the basics like food, housing, doctor visits, transportation, or heating?

Q5: For which health conditions are you currently receiving support from the PAN Foundation?	Very hard	Somewhat hard	Not hard at all	n	% Very hard/ somewhat hard	% Not hard at all
Acromegaly	7	25	5	37	86%	14%
Amyloidosis	5	23	11	39	72%	28%
Asthma	281	740	190	1,211	84%	16%
Atopic dermatitis	7	11	11	29	62%	38%
Basal cell carcinoma	7	26	17	50	66%	34%
Bladder cancer	4	21	13	38	66%	34%
Chronic lymphocytic leukemia	37	235	218	490	56%	44%
Colorectal cancer	23	47	15	85	82%	18%
COVID-19 treatment and prevention	105	132	14	251	94%	6%
Cushing's disease or syndrome	2	3	3	8	63%	38%
Fabry disease	3	3	0	6	100%	0%
Fabry disease premium	0	1	1	2	50%	50%
Gaucher disease	3	1	2	6	67%	33%
Glioblastoma multiforme	2	4	3	9	67%	33%
Heart failure	126	544	159	829	81%	19%
Hemophilia	15	26	12	53	77%	23%
Hemophilia premium	8	4	2	14	86%	14%
Hepatitis C	31	107	35	173	80%	20%
Hypercholesterolemia	24	65	27	116	77%	23%
Hyperkalemia	19	93	38	150	75%	25%
Immune thrombocytopenic purpura	7	26	12	45	73%	27%
Immune thrombocytopenic purpura travel	3	1	0	4	100%	0%
Inflammatory bowel disease	17	45	15	77	81%	19%
Inherited retinal disease	5	11	1	17	94%	6%
Inherited retinal disease premium	1	3	1	5	80%	20%
Inherited retinal disease travel	1	2	1	4	75%	25%
Macular diseases	12	26	14	52	73%	27%
Mantle cell lymphoma	1	39	21	61	66%	34%
Melanoma	8	30	16	54	70%	30%
Metastatic breast cancer	28	123	72	223	68%	32%
Multiple myeloma	37	83	53	173	69%	31%
Multiple sclerosis	153	629	350	1,132	69%	31%
Neurotrophic keratitis	8	25	21	54	61%	39%
Neutropenia	4	4	2	10	80%	20%
Non-small cell lung cancer	14	40	20	74	73%	27%
Ovarian cancer	4	21	14	39	64%	36%
Parkinson's disease	75	436	227	738	69%	31%
Philadelphia chromosome negative myeloproliferative neoplasms	9	71	63	143	56%	44%
Postmenopausal osteoporosis	18	43	22	83	73%	27%
Prostate cancer	98	528	336	962	65%	35%
Pulmonary hypertension	67	194	66	327	80%	20%
Renal cell carcinoma	12	46	18	76	76%	24%
Retinal vein occlusion	9	14	17	40	58%	43%
Rheumatoid arthritis	56	90	15	161	91%	9%
Short bowel syndrome	4	8	1	13	92%	8%
Short bowel syndrome premium	4	5	1	10	90%	10%
Sickle cell disease	3	7	2	12	83%	17%
Tuberous sclerosis complex	0	4	0	4	100%	0%
Uveitis	7	14	2	23	91%	9%
Venous leg ulcers	4	11	1	16	94%	6%
Waldenstrom macroglobulinemia	5	19	22	46	52%	48%
Totals	**1,383**	**4,709**	**2,182**	**8,274**		

Disease fund	Food: I have limited or uncertain access to enough food or to nutritious food.		Housing and utilities: I have difficulty with housing, paying rent or mortgage, or paying for my phone or utility bills.		Housing and utilities: I am concerned about the cost of housing and utilities.		Healthcare: I have difficulty paying for health care services other than prescription medications.		Healthcare: I am concerned about paying for visits to the doctor or dentist.		Social support networks: I am alone most of the time.		Daily activities: I need help with basic day-to-day activities.		Daily activities: I am concerned about being able to do basic activities that allow me to live		Transportation: I have difficulty accessing or affording transportation to get to doctor appointments, or the pharmacy.	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Acromegaly	9	29%	11	37%	17	61%	17	57%	19	70%	11	41%	8	30%	11	39%	1	4%
Amyloidosis	9	33%	8	30%	12	48%	14	54%	12	48%	7	28%	8	32%	11	44%	1	4%
Asthma	357	35%	432	43%	636	69%	599	61%	646	71%	421	46%	222	24%	447	46%	152	16%
Atopic dermatitis	9	53%	9	53%	9	60%	14	88%	12	80%	7	47%	3	20%	8	53%	3	20%
Basal cell carcinoma	10	31%	13	41%	18	60%	16	50%	19	66%	13	46%	8	29%	14	45%	9	30%
Bladder cancer	7	29%	6	25%	12	52%	12	52%	14	61%	7	30%	2	9%	6	26%	0	0%
Chronic lymphocytic leukemia	47	17%	67	25%	144	59%	122	47%	135	55%	65	27%	34	14%	103	40%	21	8%
Colorectal cancer	29	42%	35	52%	50	78%	48	73%	45	70%	20	31%	19	30%	26	40%	11	17%
COVID-19 treatment and prevention	163	69%	172	74%	180	83%	135	59%	147	68%	129	61%	75	35%	114	50%	88	40%
Cushing's disease or syndrome	1	20%	3	60%	3	75%	4	80%	4	100%	3	75%	3	75%	3	60%	0	0%
Fabry disease	4	67%	5	83%	4	100%	3	60%	3	75%	2	50%	2	50%	5	100%	1	25%
Fabry disease premium	0	0%	0	0%	N/A	N/A	0	0%	0	N/A	N/A	N/A	N/A	N/A	1	100%	0	N/A
Gaucher disease	2	50%	4	100%	3	100%	4	100%	3	100%	3	100%	0	0%	2	50%	3	75%
Glioblastoma multiforme	3	50%	4	67%	5	83%	6	100%	4	67%	3	50%	3	50%	4	67%	1	17%
Heart failure	180	27%	246	37%	407	67%	345	53%	379	63%	215	36%	127	21%	304	49%	75	12%
Hemophilia	15	37%	23	58%	29	78%	28	72%	25	68%	8	22%	11	30%	19	50%	4	11%
Hemophilia premium	5	42%	7	58%	7	70%	11	92%	8	89%	3	33%	1	11%	4	36%	1	9%
Hepatitis C	47	34%	63	47%	94	74%	93	71%	93	74%	48	38%	25	20%	50	39%	23	18%
Hypercholesterolemia	29	33%	37	43%	62	76%	44	52%	50	61%	35	43%	14	17%	38	45%	12	14%
Hyperkalemia	28	25%	36	33%	53	55%	49	45%	52	54%	35	37%	24	26%	51	49%	14	14%
Immune thrombocytopenic purpura	9	27%	11	33%	16	52%	19	58%	19	61%	8	27%	6	20%	13	41%	5	16%
Immune thrombocytopenic purpura travel	3	75%	3	75%	3	75%	4	100%	4	100%	2	50%	1	25%	2	50%	2	50%
Inflammatory bowel disease	24	39%	26	43%	38	68%	40	69%	37	67%	29	54%	7	13%	28	48%	11	19%
Inherited retinal disease	6	38%	7	44%	10	67%	13	81%	13	87%	3	20%	2	13%	3	19%	1	6%
Inherited retinal disease premium	2	50%	2	50%	1	25%	1	33%	3	75%	2	50%	0	0%	1	25%	1	25%
Inherited retinal disease travel	1	33%	1	33%	2	67%	2	67%	2	67%	1	33%	0	0%	2	67%	1	33%
Macular diseases	12	32%	16	42%	25	69%	24	63%	28	78%	14	40%	12	34%	21	57%	4	11%

	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Mantle cell lymphoma	4	10%	12	31%	27	79%	22	56%	23	68%	11	32%	8	24%	16	43%	4	12%
Melanoma	10	27%	14	38%	21	66%	16	46%	15	47%	13	41%	3	9%	13	37%	5	16%
Metastatic breast cancer	39	26%	57	39%	92	68%	87	60%	91	68%	50	38%	31	24%	65	46%	17	12%
Multiple myeloma	40	34%	60	51%	80	73%	71	61%	67	63%	45	42%	22	21%	48	42%	19	17%
Multiple sclerosis	202	26%	276	36%	457	66%	403	54%	464	68%	288	42%	258	38%	449	62%	123	17%
Neurotrophic keratitis	5	15%	12	38%	22	69%	19	59%	19	59%	10	31%	8	25%	10	31%	3	9%
Neutropenia	3	43%	4	57%	4	57%	4	57%	6	86%	4	57%	2	29%	4	57%	1	14%
Non-small cell lung cancer	17	32%	20	38%	35	71%	32	63%	32	65%	21	44%	12	25%	29	57%	10	20%
Ovarian cancer	7	29%	8	33%	17	74%	14	61%	16	70%	11	48%	4	17%	8	35%	2	9%
Parkinson's disease	79	16%	152	30%	300	66%	229	47%	263	59%	121	28%	244	56%	364	77%	75	16%
Philadelphia chromosome negative myeloproliferative neoplasms	12	15%	22	28%	44	58%	40	52%	41	55%	28	37%	9	12%	40	53%	8	11%
Postmenopausal osteoporosis	28	46%	31	52%	43	78%	42	72%	41	77%	36	68%	9	17%	27	47%	15	27%
Prostate cancer	122	20%	147	24%	309	55%	323	54%	332	60%	120	22%	107	19%	245	42%	47	8%
Pulmonary hypertension	94	36%	124	48%	172	72%	150	59%	148	63%	123	52%	78	33%	149	60%	47	19%
Renal cell carcinoma	12	21%	16	28%	25	50%	26	47%	32	68%	15	33%	13	29%	31	58%	10	19%
Retinal vein occlusion	8	35%	6	27%	14	70%	15	68%	13	68%	4	21%	3	16%	7	35%	4	20%
Rheumatoid arthritis	65	45%	91	63%	112	80%	95	66%	107	78%	78	58%	44	33%	83	58%	38	27%
Short bowel syndrome	5	42%	6	50%	9	75%	8	67%	10	83%	6	55%	2	18%	9	75%	3	25%
Short bowel syndrome premium	5	56%	5	56%	7	78%	6	67%	7	78%	5	56%	2	22%	3	33%	2	22%
Sickle cell disease	6	60%	8	80%	8	80%	6	60%	9	100%	6	67%	1	11%	4	40%	5	50%
Tuberous sclerosis complex	0	0%	1	25%	2	67%	1	33%	3	100%	0	0%	2	100%	3	100%	0	0%
Uveitis	11	52%	15	71%	19	90%	15	71%	16	80%	11	55%	8	40%	11	52%	6	29%
Venous leg ulcers	8	53%	7	47%	10	77%	9	60%	10	83%	4	36%	3	27%	11	73%	4	31%
Waldenstrom macroglobulinemia	6	25%	10	42%	15	75%	13	57%	12	60%	10	50%	4	20%	11	52%	2	10%
Totals	**1,799**	**30%**	**2,351**	**39%**	**3,684**	**67%**	**3,313**	**57%**	**3,553**	**65%**	**2,114**	**39%**	**1,494**	**28%**	**2,931**	**51%**	**895**	**16%**

Notes

1. Each determinant had two screener questions. Food, social support networks, and transportation showed little variation between the two screeners in patients identifying with that determinant (within five percentage points). The data presented in this table was selected from the screener question which elicited the greater response in total patient identification across all disease funds.

2. Three determinants had a greater variation between the screeners in patients identifying with that determinant: healthcare (eight percentage points), housing and utilities (28 percentage points) and daily activities (23 percentage points). Both sets of responses are presented in the table.

3. Percentages are rounded up to the nearest whole number.

4. The "n" is the number of patients who identified "yes" with the determinant. The "%" represents the percentage of patients who identified with the determinant divided by the sum of all patients who answered the question (both yes and no responses).

5. The "n" varies because patients dropped out at various points in the survey so did not answer all the questions relating to the determinants.

6. Values of "N/A" are used when all patients skipped the question (i.e. neither "yes" nor "no" were selected). This differs from "zero" which is used when all patients answered "no" and zero patients answered "yes."

Appendix C: Survey Questions

1. What is your current age?
   - ☐ Under 35
   - ☐ 35-44
   - ☐ 45-54
   - ☐ 55-64
   - ☐ 65-74
   - ☐ 75-84
   - ☐ 85+

2. Please indicate your gender
   - ☐ Female
   - ☐ Male

3. What is your highest level of education?
   - ☐ Less than high school
   - ☐ High school graduate
   - ☐ Some college
   - ☐ College graduate
   - ☐ Graduate or professional degree

4. What is your current Zip Code? [_____ Free Text]

5. For which health conditions are you currently receiving support from the PAN Foundation?
   Check all that apply.

☐ Acromegaly	☐ Hepatitis C	☐ Non-Small Cell Lung Cancer
☐ Amyloidosis	☐ Hypercholesterolemia	☐ Ovarian Cancer
☐ Asthma	☐ Hyperkalemia	☐ Parkinson's Disease
☐ Atopic Dermatitis	☐ Immune Thrombocytopenic Purpura	☐ Philadelphia Chromosome Negative Myeloproliferative Neoplasms
☐ Basal Cell Carcinoma	☐ Immune Thrombocytopenic Purpura Travel	☐ Postmenopausal Osteoporosis
☐ Bladder Cancer	☐ Inflammatory Bowel Disease	☐ Prostate Cancer
☐ Chronic Lymphocytic Leukemia	☐ Inherited Retinal Disease	☐ Pulmonary Hypertension
☐ Colorectal Cancer	☐ Inherited Retinal Disease Premium	☐ Renal Cell Carcinoma
☐ COVID-19 Treatment and Prevention	☐ Inherited Retinal Disease Travel	☐ Retinal Vein Occlusion
☐ Cushing's Disease or Syndrome	☐ Macular Diseases	☐ Rheumatoid Arthritis
☐ Fabry Disease	☐ Mantle Cell Lymphoma	☐ Short Bowel Syndrome
☐ Fabry Disease Premium	☐ Melanoma	☐ Short Bowel Syndrome Premium
☐ Gaucher Disease	☐ Metastatic Breast Cancer	☐ Sickle Cell Disease
☐ Glioblastoma Multiforme	☐ Multiple Myeloma	☐ Tuberous Sclerosis Complex
☐ Heart Failure	☐ Multiple Sclerosis	☐ Uveitis
☐ Hemophilia	☐ Neurotrophic Keratitis	☐ Venous Leg Ulcers
☐ Hemophilia Premium	☐ Neutropenia	☐ Waldenstrom Macroglobulinemia

6.   How hard is it for you to pay for any of the basics like food, housing, doctor visits, transportation, or heating? Would you say it is:
□   Very hard
□   Somewhat hard
□   Not hard at all

[if "Not hard at all" patient skips the rest of the survey. If "very hard" or "somewhat hard" they proceed to the next questions in the order indicated below.]

Are you **currently** experiencing any of the following problems? Please check all statements that apply to you **at the current time**.

7.   I have limited or uncertain access to enough food or to nutritious food (Yes/No)
[if yes, answer next question]

8.   Please check all boxes that apply to you
□   I am sometimes worried that my food will run out before I have money to buy more
□   I can't afford to buy nutritious food
□   It is hard for me to get to places where I can buy nutritious food

9.   I have difficulty with housing, paying rent or mortgage, or paying for my phone or utility bills (Yes/No)
[if yes, answer next question]

10.   Please check all boxes that apply to you
□   I have trouble making my rent or paying my mortgage
□   I have a place to live now, but I am worried about losing it in the future
□   I have trouble paying my phone bill
□   I have trouble paying my Internet bill
□   I have trouble pay my electricity, gas, or water bills

11.   I have difficulty paying for health care services other than prescription medications (Yes/No)
[if yes, answer next question]

12.   Please check all boxes that apply to you
□   I have trouble paying for my doctor bills
□   I have trouble paying for dental care

13.   I feel isolated or cut off from family, friends, and neighbors (Yes/No)
[if yes, answer next question]

14.   Please check all boxes that apply to you
□   I spend most of my time alone, but I would rather socialize with other people more often
□   I don't have anyone to help me in case of emergency
□   I need someone to check in on me from time to time

15.   I am concerned about being able to do basic activities that allow me to live independently (Yes/No)
[if yes, answer next question]

16. Please check all boxes that apply to you
    ☐ I need help with eating, bathing, dressing, walking, or using the toilet
    ☐ I need help with shopping, preparing food, housekeeping, laundry, finances, or managing my medications

17. I have difficulty accessing or affording transportation to get to doctor appointments, the pharmacy, or to get to work (Yes/No)
    [if yes, answer next question]

18. Please check all boxes that apply to you
    ☐ I can't get to important appointments or places because I can't afford transportation
    ☐ I can't get to important appointments or places because I can't access transportation

19. The COVID-19 pandemic has made it harder for me to pay for the basics like food, housing, doctor visits, transportation, or heating.
    [if yes, answer next question]

20. Please check all boxes that apply to you. COVID-19 has made it harder for me to pay for:
    ☐ Food
    ☐ My rent or mortgage
    ☐ My utility bills like heat, air-conditioning, electric, and phone
    ☐ Doctor or dentist visits
    ☐ Transportation

21. I am concerned about having enough food. (Yes/No)
    [if yes, answer next question]

22. Please check all boxes that apply to you
    ☐ I am sometimes worried that my food will run out before I have money to buy more
    ☐ I can't afford to buy nutritious food
    ☐ It is hard for me to get to places where I can buy nutritious food

23. I am concerned about the cost of housing and utilities. (Yes/No)
    [if yes, answer next question]

24. Please check all boxes that apply to you
    ☐ I have trouble making my rent or paying my mortgage
    ☐ I have a place to live now, but I am worried about losing it in the future
    ☐ I have trouble paying my phone bill
    ☐ I have trouble pay my electricity or water bill

25. I am concerned about paying for visits to the doctor or dentist (Yes/No)
    [if yes, answer next question]

26. Please check all boxes that apply to you
    ☐ I have trouble paying for my doctor bills
    ☐ I have trouble paying for dental care

27.   I am alone most of the time (Yes/No)
[if yes, answer next question]

28.   Please check all boxes that apply to you
- ☐ I spend most of my time alone, but I would rather socialize with other people more often
- ☐ I don't have anyone to help me in case of emergency
- ☐ I need someone to check in on me from time to time

29.   I need help with basic day-to-day activities (Yes/No)
[if yes, answer next question]

30.   Please check all boxes that apply to you
- ☐ I need help with eating, bathing, dressing, walking, or using the toilet
- ☐ I need help with shopping, preparing food, housekeeping, laundry, finances, or managing my medications

31.   Lack of reliable transportation has kept me from getting to medical appointments, work, or getting things I need for daily living. (Yes/No)
[if yes, answer next question]

32.   Please check all boxes that apply to you
- ☐ I can't get to important appointments or places because I can't afford transportation
- ☐ I can't get to important appointments or places because I can't access transportation

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