



CANCER SUPPORT HELPLINE PROACTIVE NAVIGATION ANNUAL REPORT

2023



The Helpline received calls from **4,680** new callers out of the Total Helpline activity of **24,992**. The average call time is **12:31** and average wait time is **0:28** Seconds.

24,992

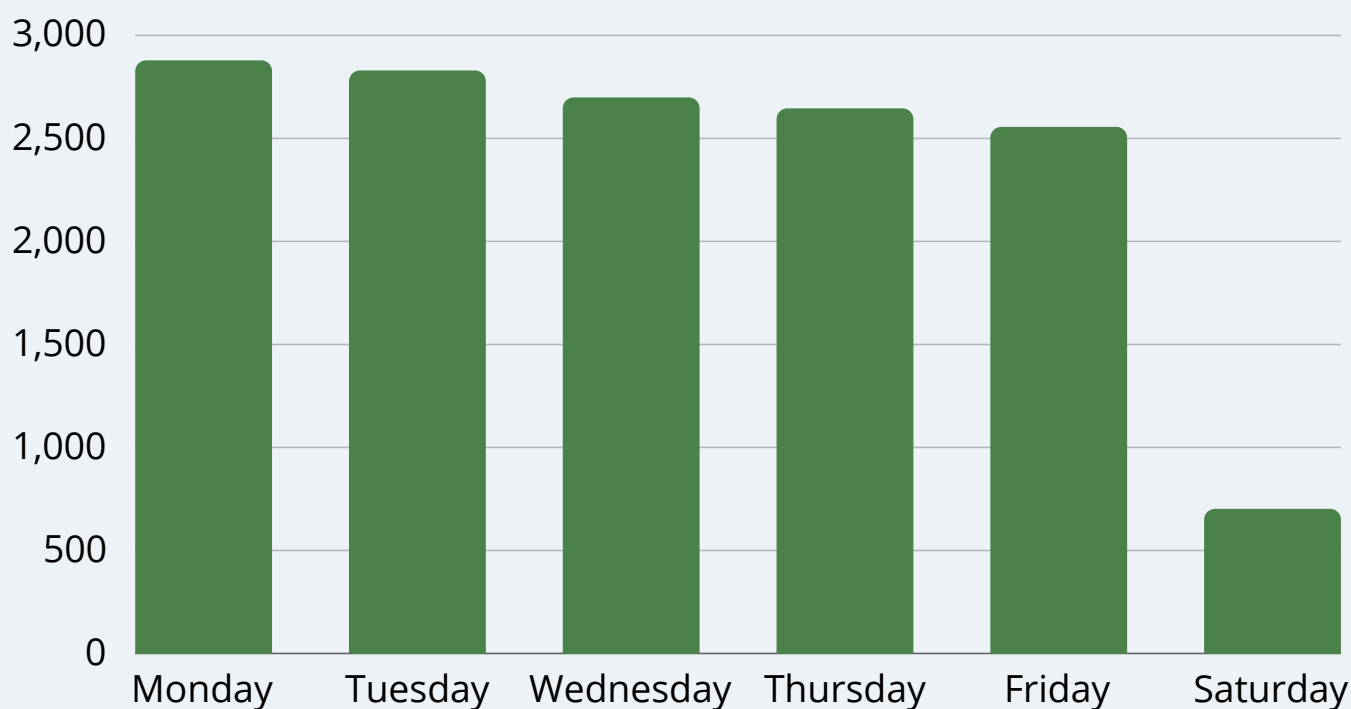
Total Volume

Peak Call Day: **Tuesday**
Lowest Call Day: **Friday**

8,080
Outbound Calls

399
Chats

1,138
Emails



Referrals Completed

Network Partner	954
Financial Navigation	264
Translation/Bilingual Navigation	96
Pediatric Oncology Navigation	48
Clinical Trials Navigation	57
Genetic Specialist	15
Open to Options	15

"The navigator was excellent and a huge help. I felt heard and understood as she allowed me to have time to discuss all the things that were important to me with great insight and experience. The navigator is a true asset, and I am so happy she answered my call today!"

Cancer Support Helpline® Caller

Post-Call Survey

559 surveys completed

4.58/5

The Navigator seemed to listen and understand my concerns.

4.28/5

The provided education materials were relevant to my needs or aligned with my needs.

4.4/5

Working with my Navigator was valuable.

4.5/5

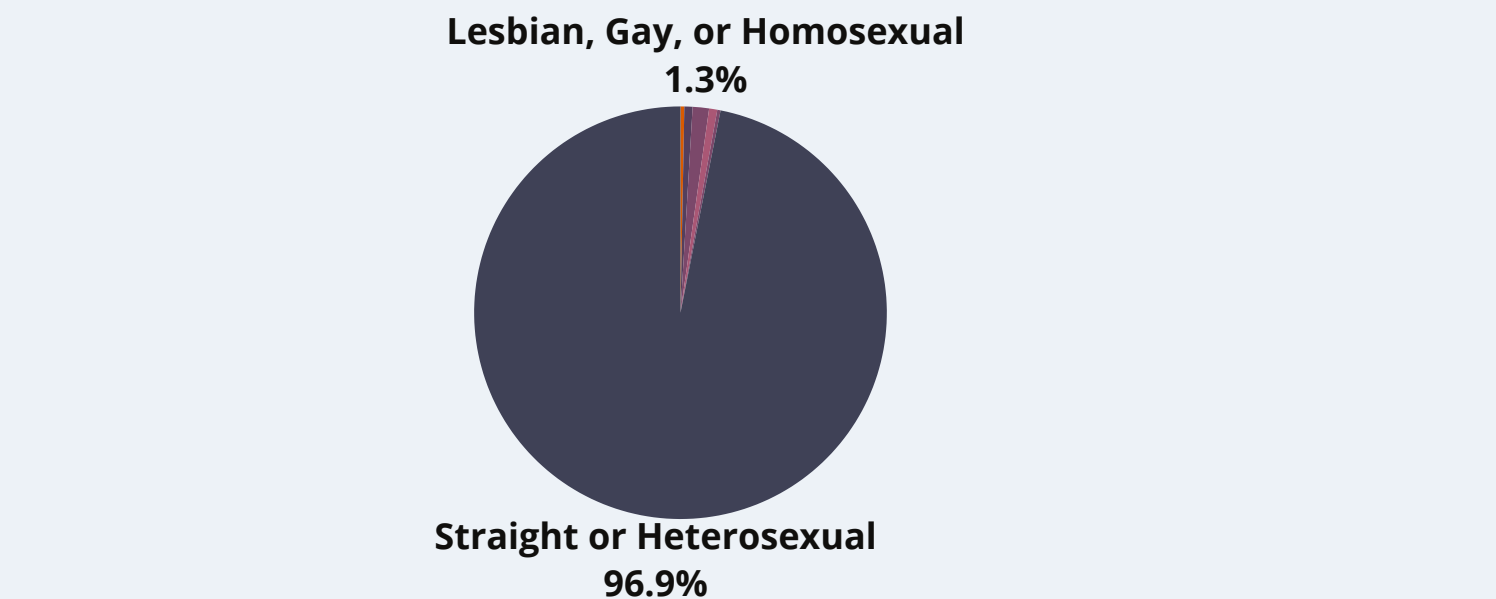
I would recommend this service to others.

CALLER DEMOGRAPHICS

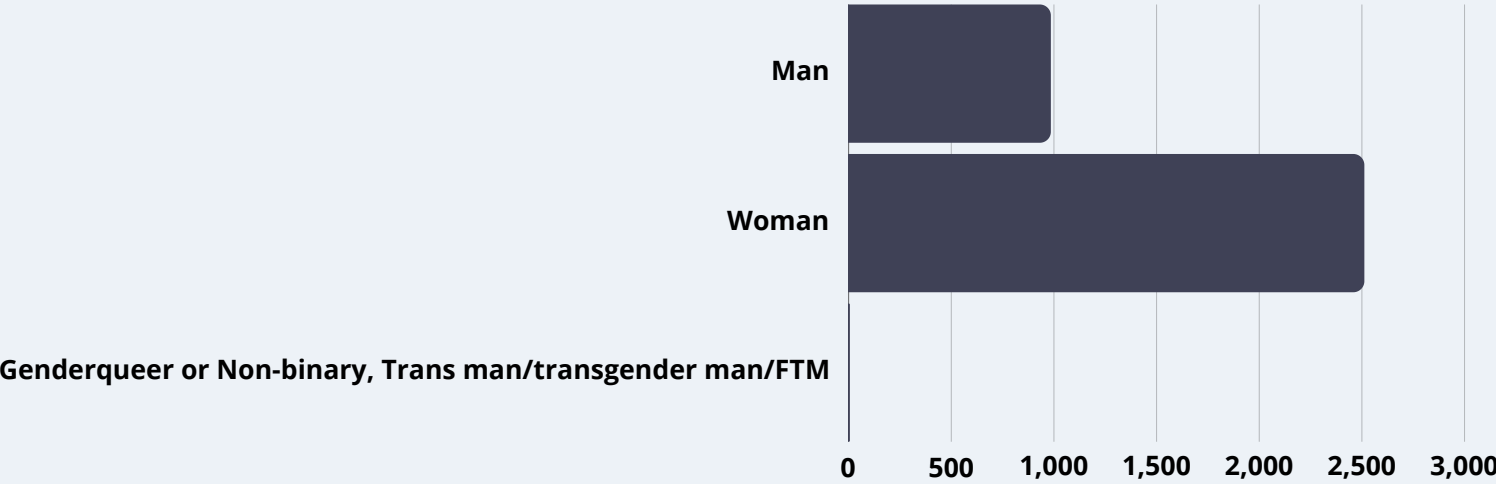


1ST TIME CALLER DEMOGRAPHICS

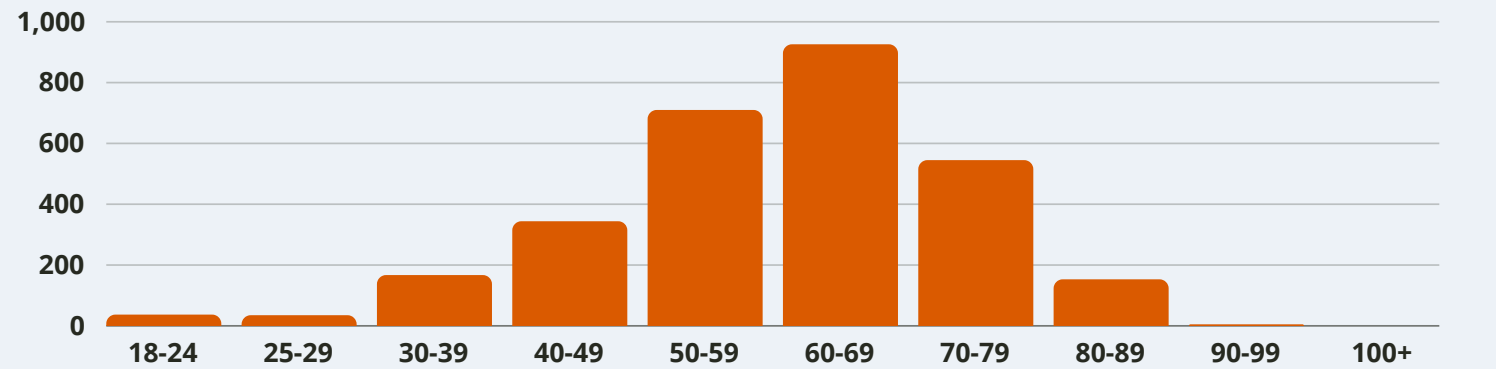
Sexual Identity



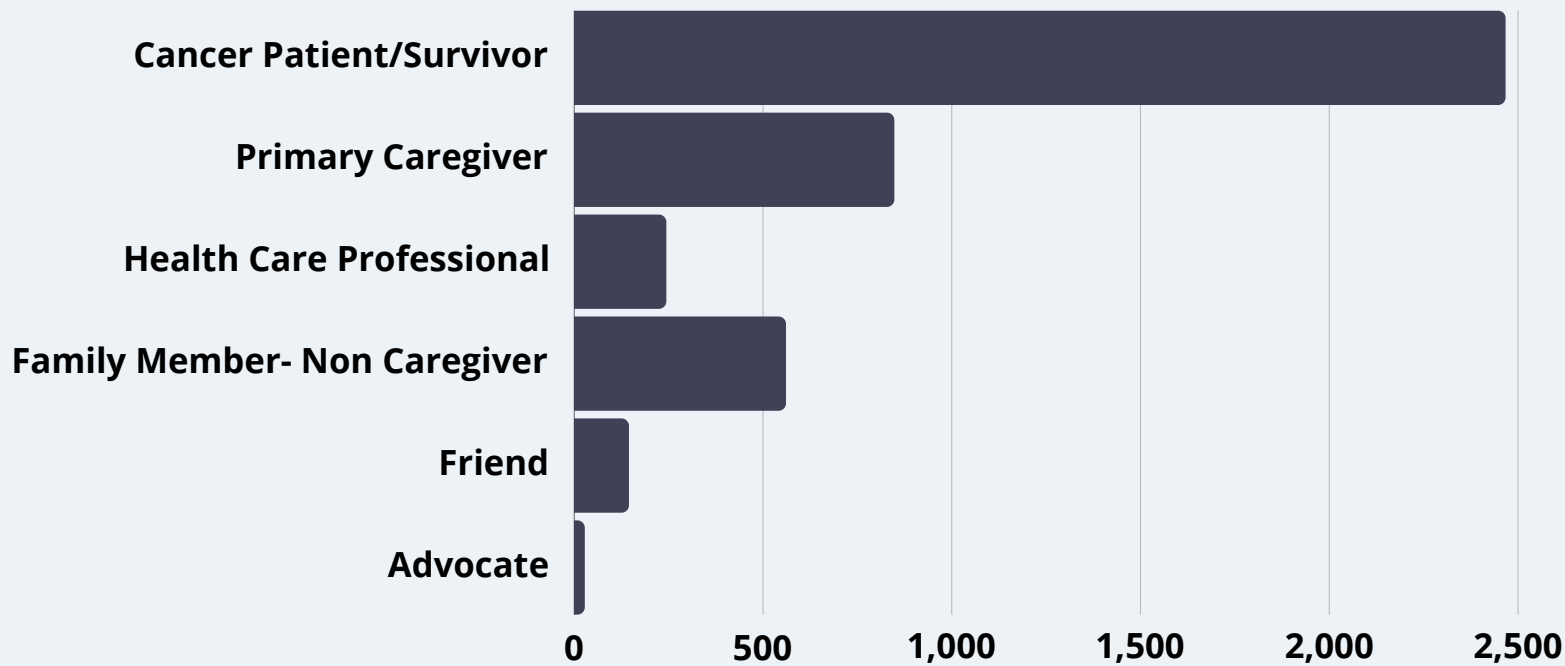
Gender Identity



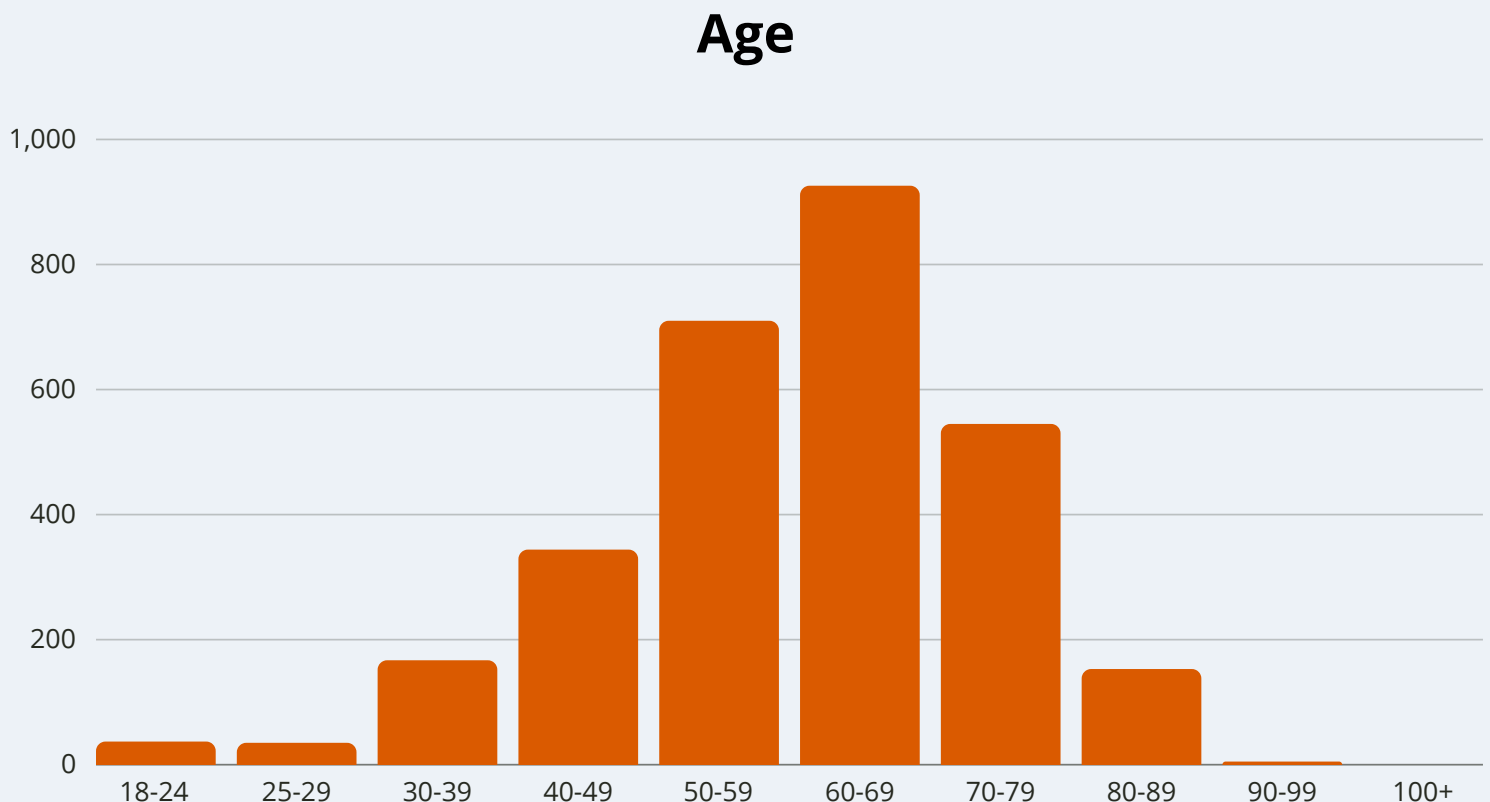
Age



1ST TIME CALLER TYPES

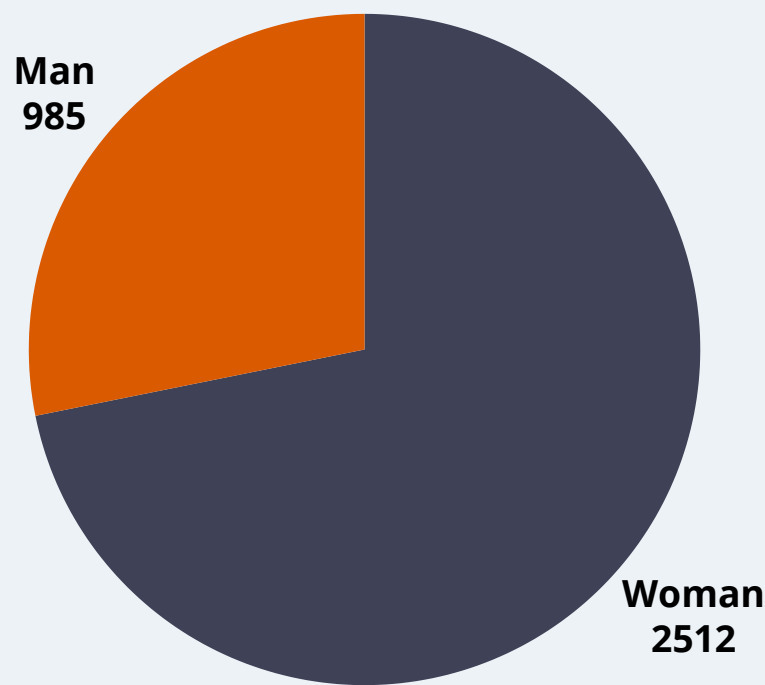


1ST TIME CALLER DEMOGRAPHICS

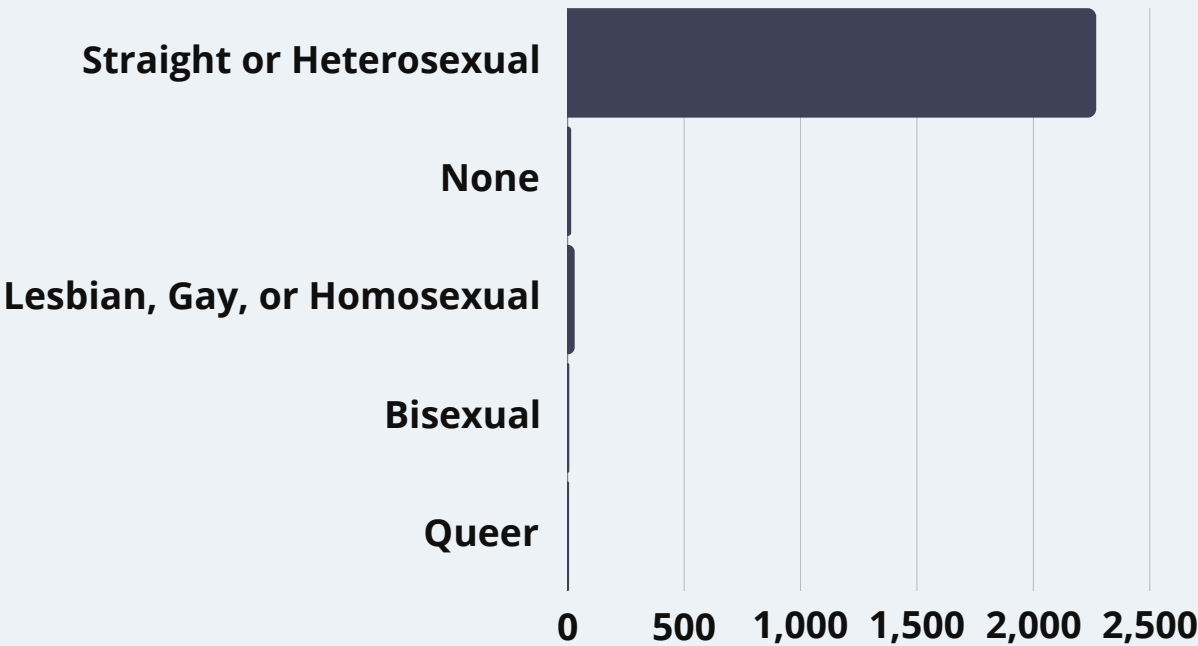


1ST TIME CALLER DEMOGRAPHICS

Gender Identity



Sexual Identity



1ST TIME CALLER **DEMOGRAPHICS**

The primary language spoken by most callers is **English**.

Other primary languages represented include: Spanish (n=119), Russian (n=4), Korean (n=2), Mandarin Chinese (n=5), Amharic (n=2), Polish (n=1), and Vietnamese (n=1).

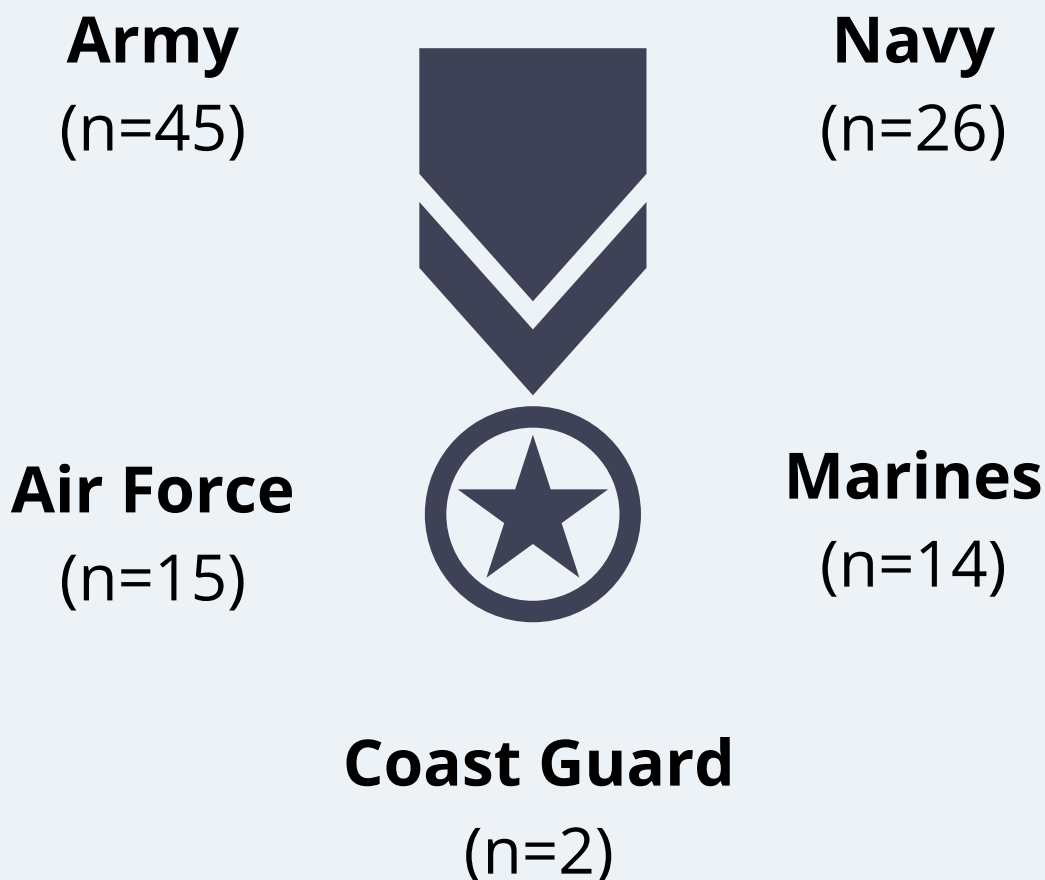


1ST TIME CALLER DEMOGRAPHICS

Veterans

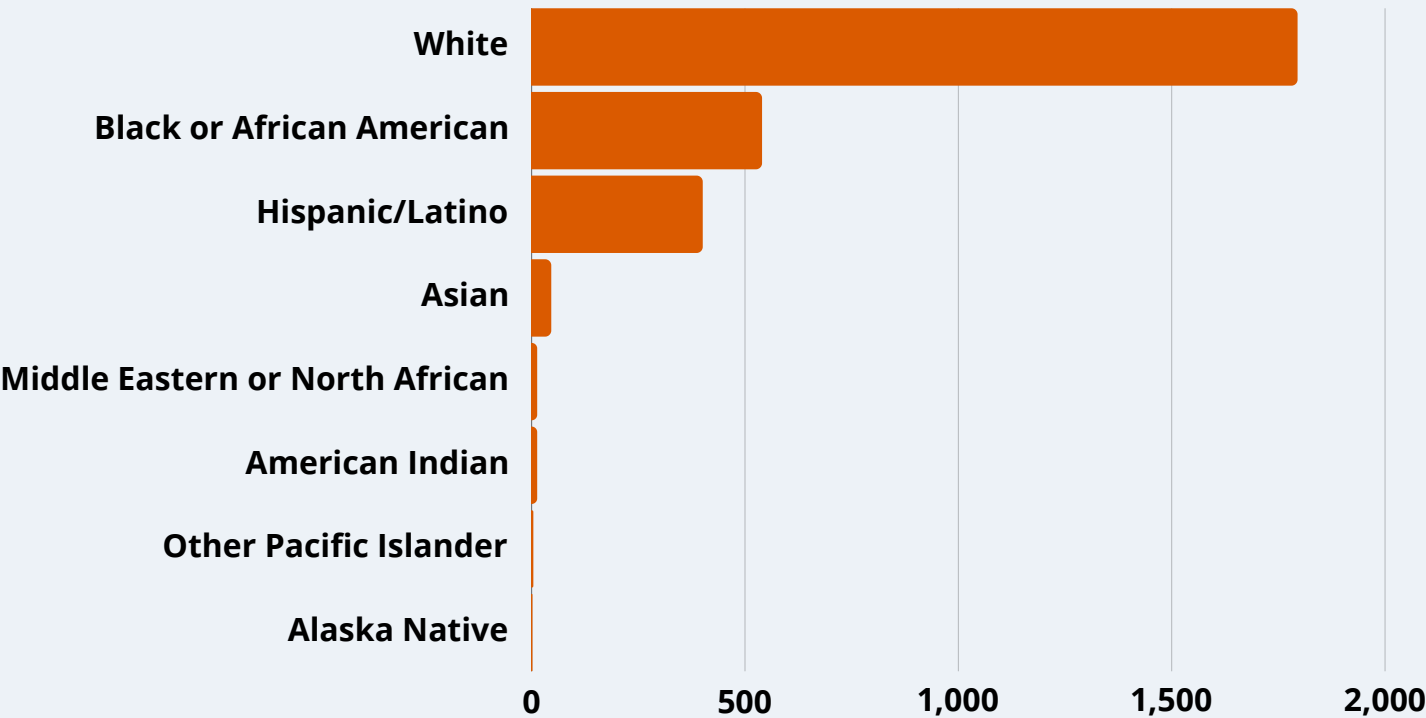
Total number served: **114**

Branches Served:



1ST TIME CALLER DEMOGRAPHICS

Race/Ethnicity



Ethnicity: Hispanic

Mexican, Mexican American, or Chicano(a)
(n=127)

South American
(n=28)

Central American
(n=11)

Dominican (Republic)
(n=11)

Salvadoran
(n=6)



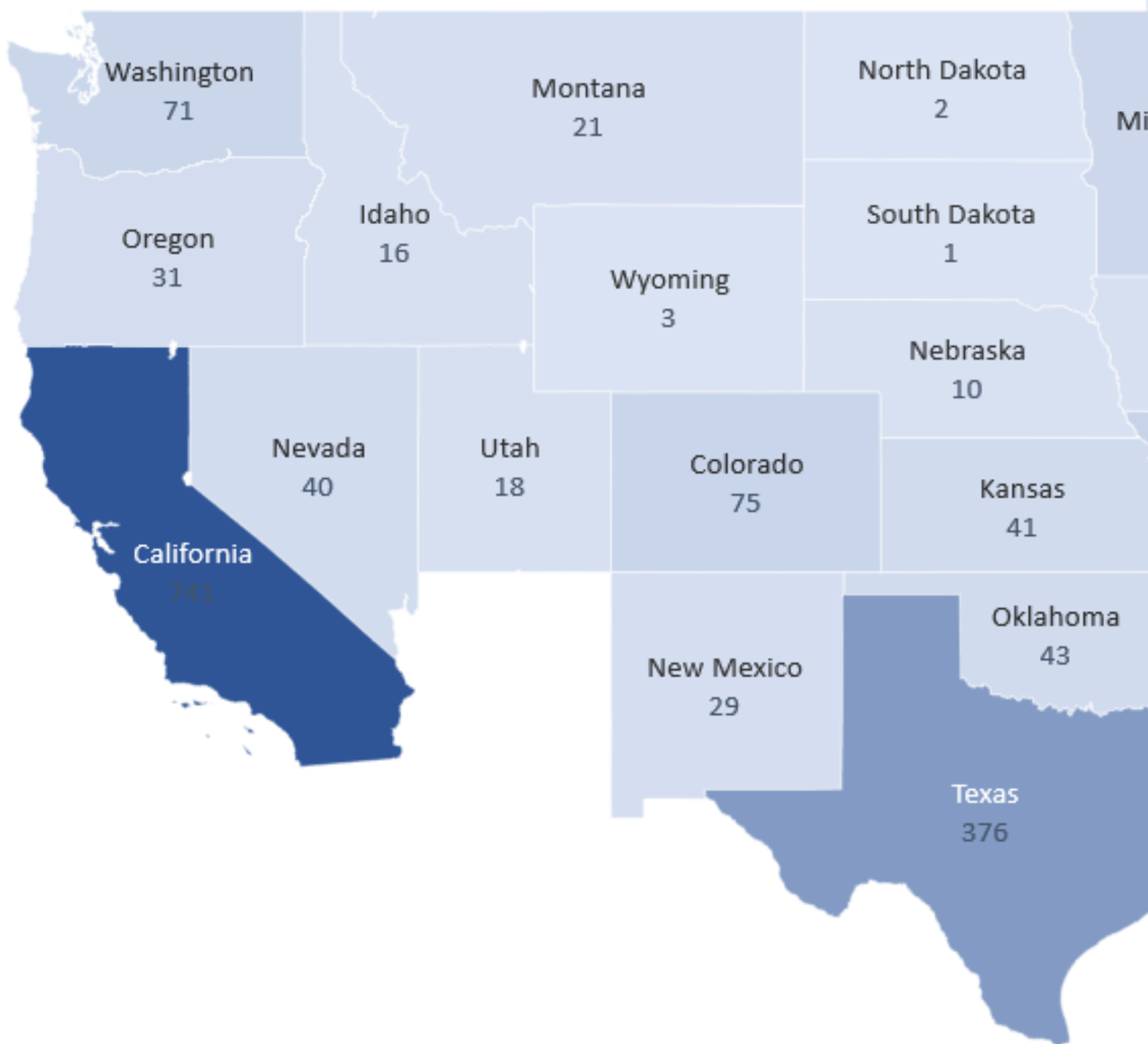
Puerto Rican
(n=25)

Honduran
(n=3)

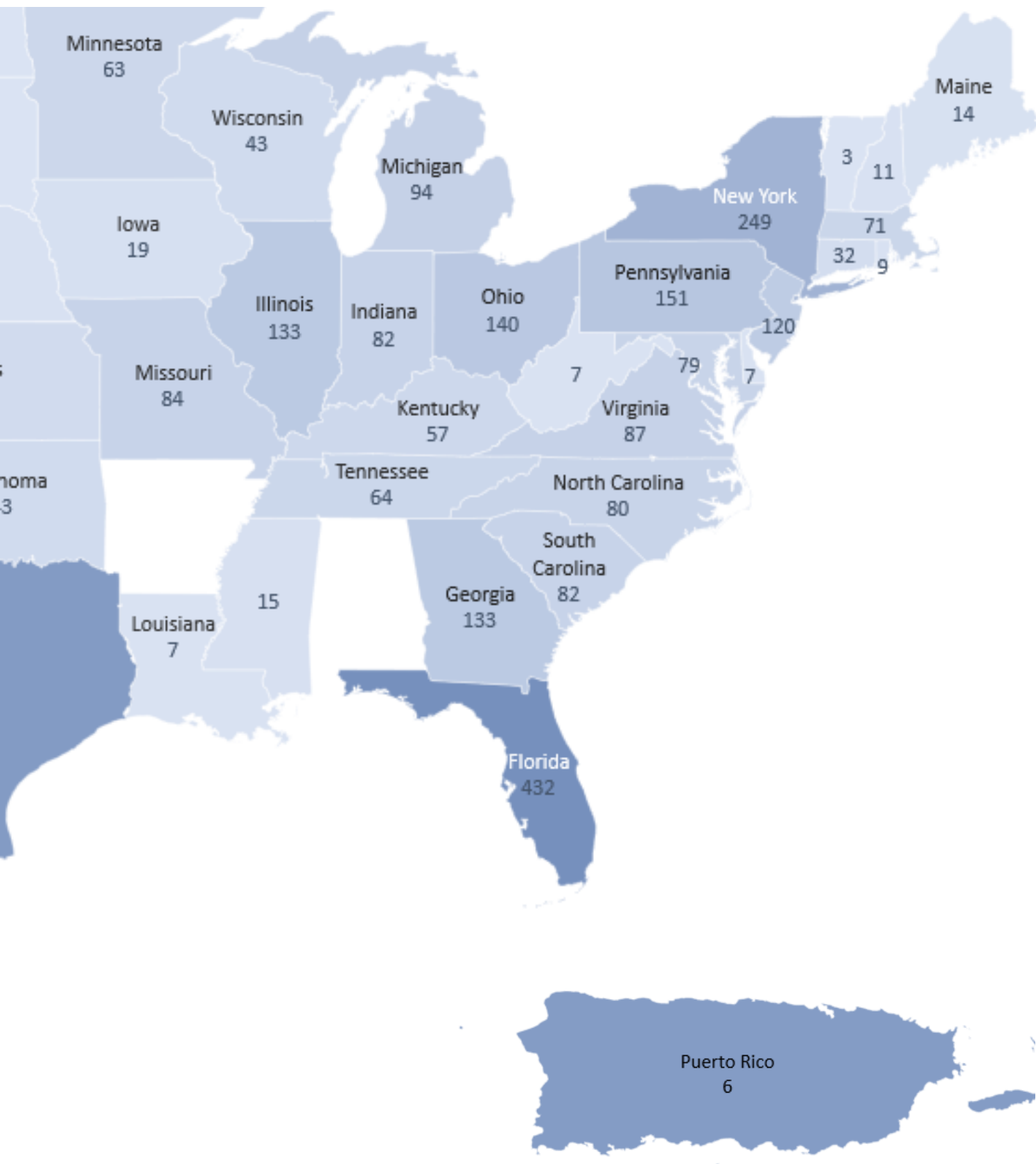
Columbian
(n=7)

Cuban
(n=9)

WHERE DID THEY CALL FROM?



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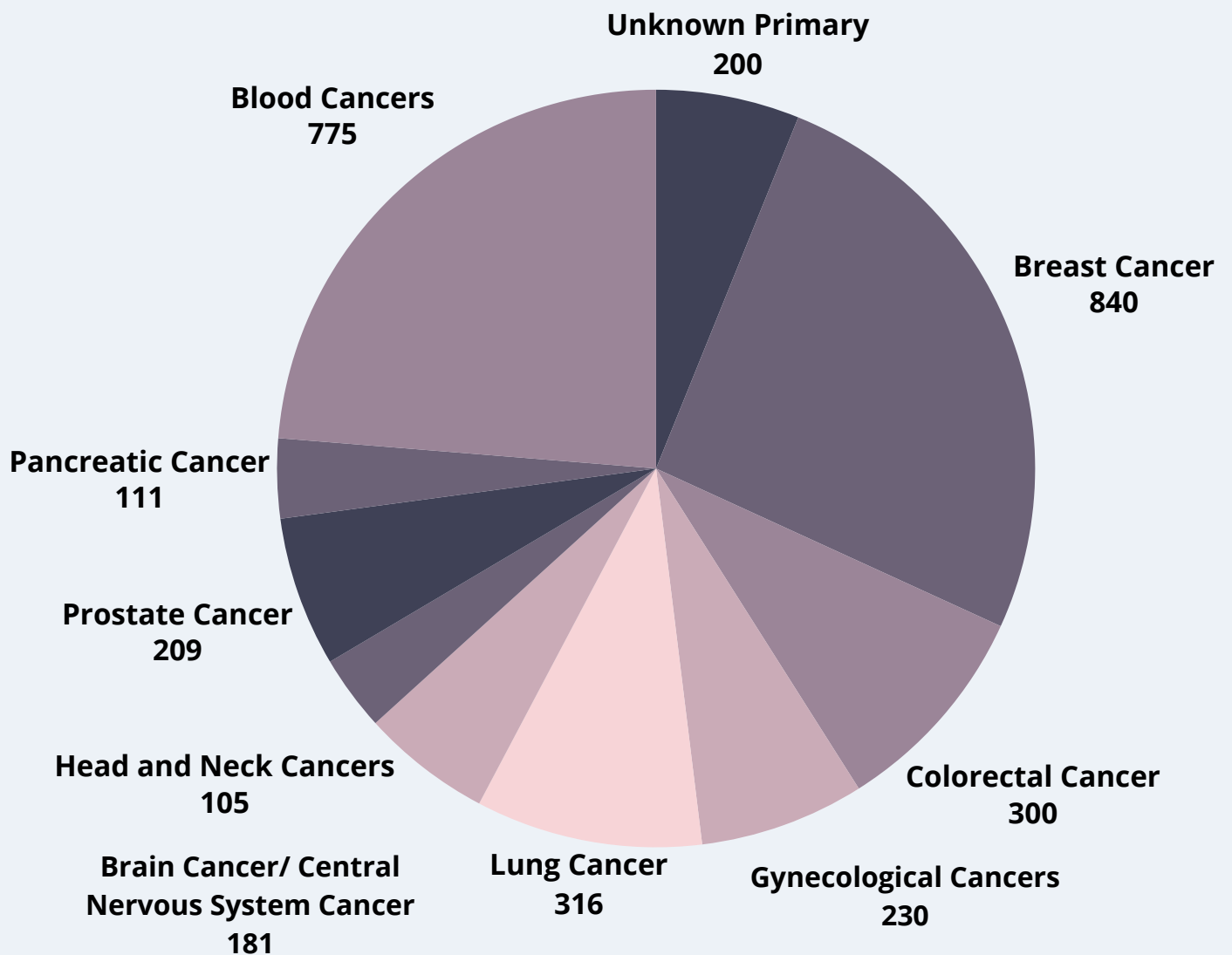
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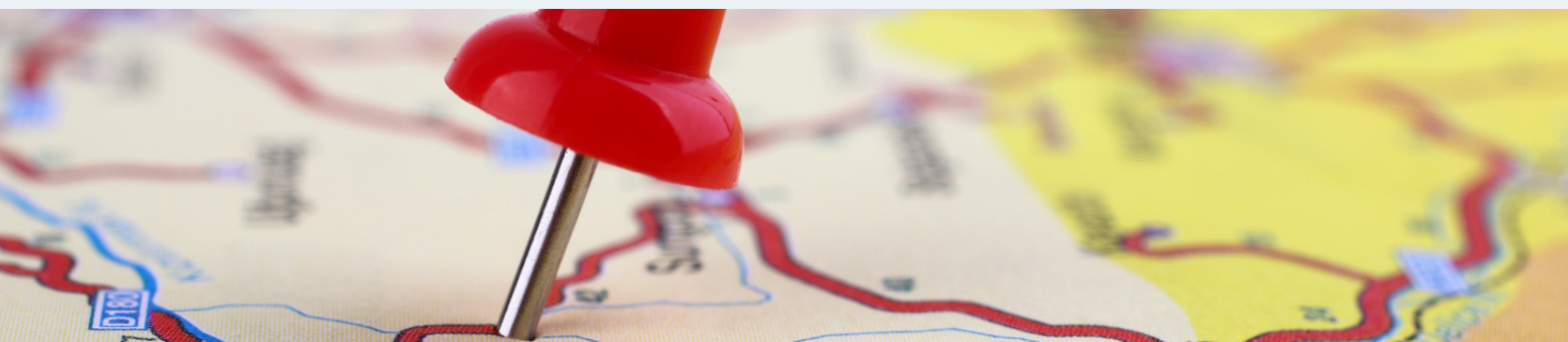
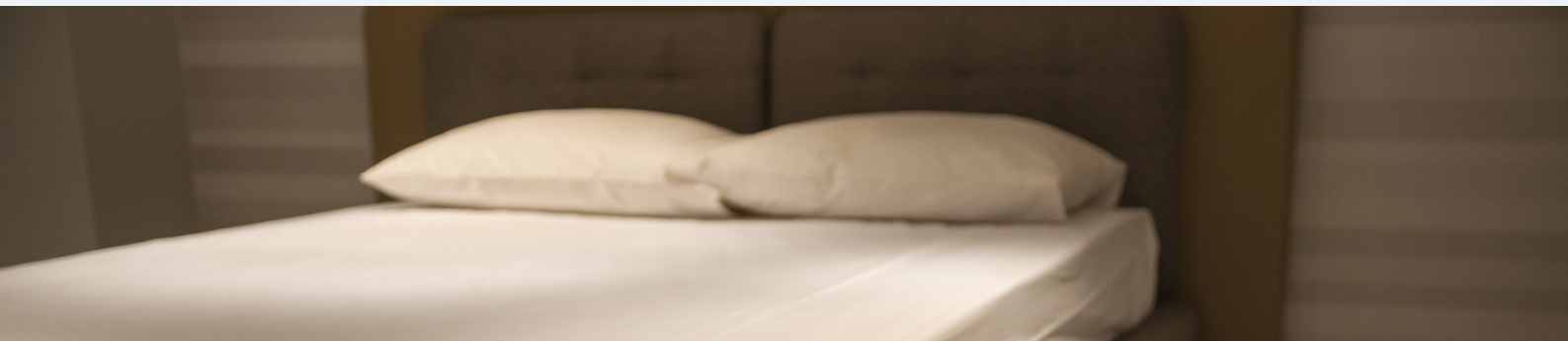
TOP 5 REPORTED CANCER DIAGNOSIS



TOP 10 REPORTED CANCER DIAGNOSIS OF *NEW CALLERS*



TOP 5 INITIAL REASONS FOR CALL



TOP **5** INITIAL REASONS FOR CALL

Seeking Support & Coping with Emotions

1,272 Callers

Financial Stressors

(Health Insurance, Medical Bills, Household Expenses)

1,179 Callers

Lodging During Treatment

896 Callers

Transportation for Treatment

470 Callers

Find a CSC

127 Callers

CancerSupportSource® (CSS) Patient

696

Callers Screened

TOP 5 CONCERNS

% of respondents that were moderately-very seriously concerned

64%

Worrying about the future and what lies ahead

81% of callers requested additional support for this concern

59%

Changes in work, school or home life

75% of callers requested additional support for this concern

56%

Feeling nervous or afraid

86% of callers requested additional support for this concern

56%

Feeling sad or depressed

71% of callers requested additional support for this concern

55%

Health insurance or money worries

76% of callers requested additional support for this concern

CancerSupportSource® (CSS) Caregiver

150

Callers Screened

TOP 5 CONCERNS

% of respondents that were moderately-very seriously concerned

66%

Worrying about the future and what lies ahead

94% of callers requested additional support for this concern

57%

Worrying about changes in the patient's eating and nutrition

73% of callers requested additional support for this concern

54%

Changes or disruptions in work, school or home life

76% of callers requested additional support for this concern

52%

Feeling sad or depressed

79% of callers requested additional support for this concern

51%

Feeling nervous or afraid

77% of callers requested additional support for this concern

EVALUATED BARRIERS



TOP EVALUATED BARRIERS

Emotional Well Being

Sadness

505 callers

Access to Support

487 Callers

History of Anxiety or Depression

416 Callers

Frustration

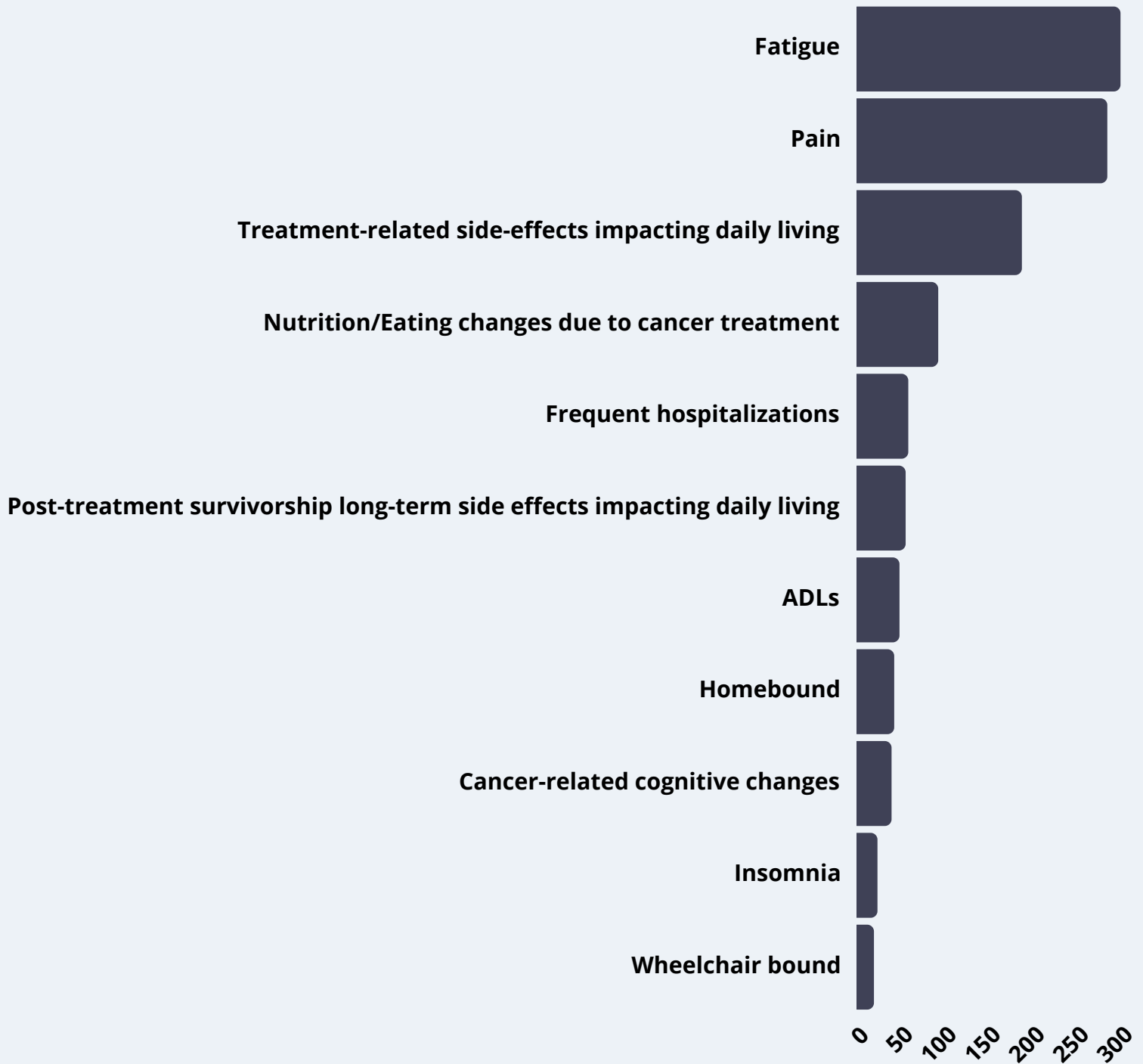
355 Callers

Fear of Treatment

207 Callers

TOP EVALUATED BARRIERS

Symptom Burden and Impact



EVALUATED BARRIERS

Body Image and Healthy Lifestyle



203 callers

Concerned with the health of other family members

159 Callers

Concerned with their appearance; including hair loss

67 callers

Concerned with weight change

65 callers

Concerned with exercising

EVALUATED BARRIERS

Financial Toxicity: Medical



79 Callers

RX Access and Cost

547 Callers

Uninsured Underinsured
Copays and Deductibles
Insurance Questions

1,230 Callers

Lodging and Transportation Access
for Cancer Treatment

Financial Toxicity: Home and Work



874 Callers

Reported concerns with work,
employment, or ability to pay
household bills

61 Callers

Reported concerns with legal
issues or immigration status

238 Callers

Reported concerns with food insecurity

97 Callers

reported a history of or current
unhoused/homelessness

EVALUATED BARRIERS

Health Care Team Communication



137 Callers

reported mistrust toward health care team

99 Callers

wanted information on second opinions

89 Callers

wanted information about palliative or end-of-life care

80 Callers

reported a lack of understanding or confusion about cancer treatment options

52 Callers

wanted help with Health Literacy (including unable to read)

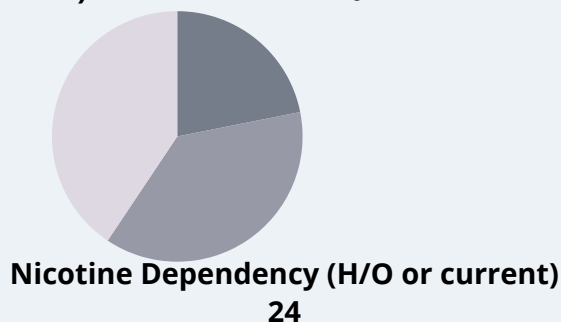
40 Callers

wanted help with clinical trials information and or access

Tobacco and Substance Abuse

Self: Substance Dependency (H/O or current)
26

Family: Substance Dependency (H/O or current)
14



NAVIGATION INTERVENTIONS

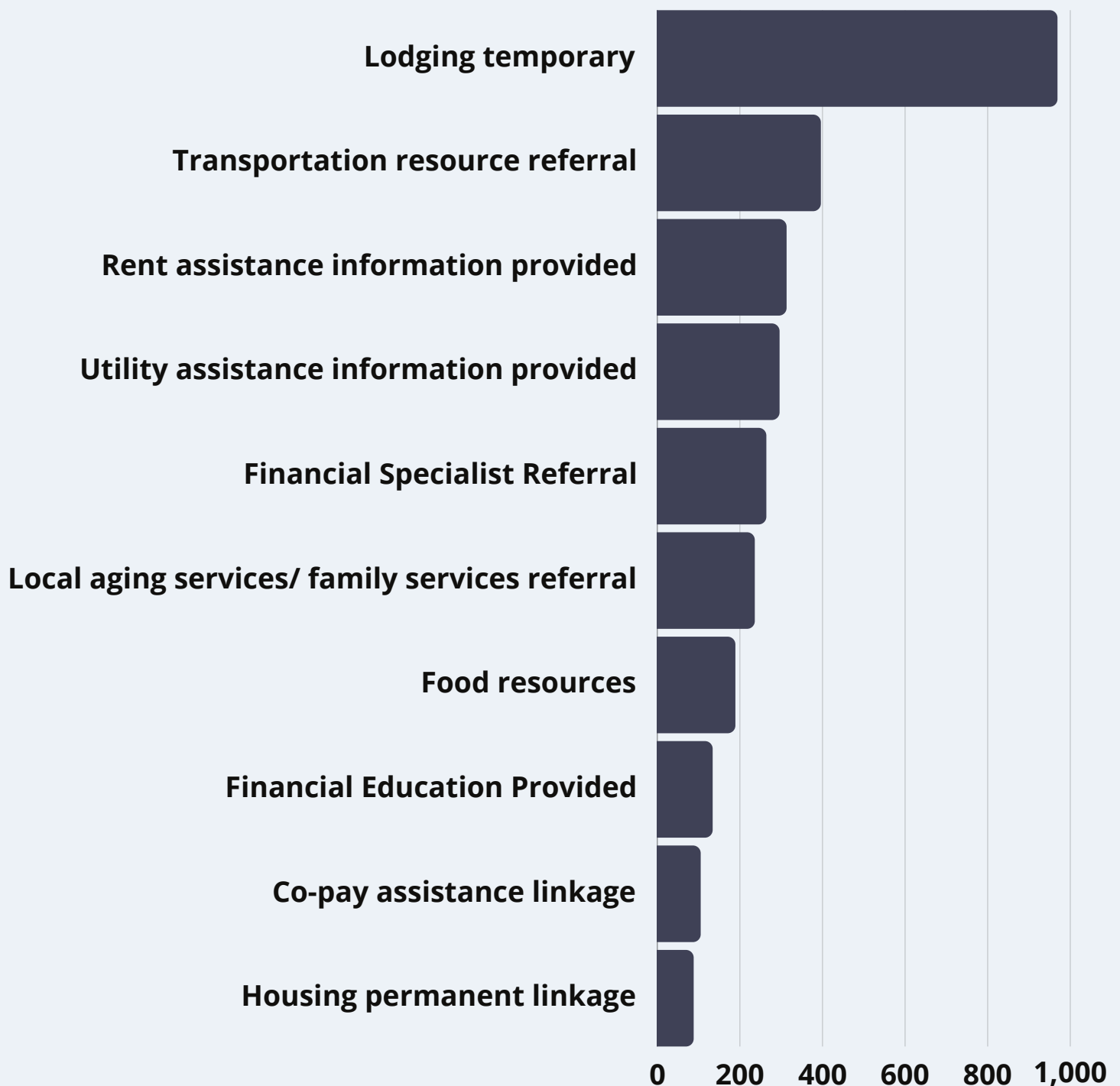


NAVIGATION INTERVENTIONS



Financial Toxicity

Helpline navigators and specialists completed many interventions to assist callers experiencing financial toxicity. In total, **2,990** such interventions were completed.

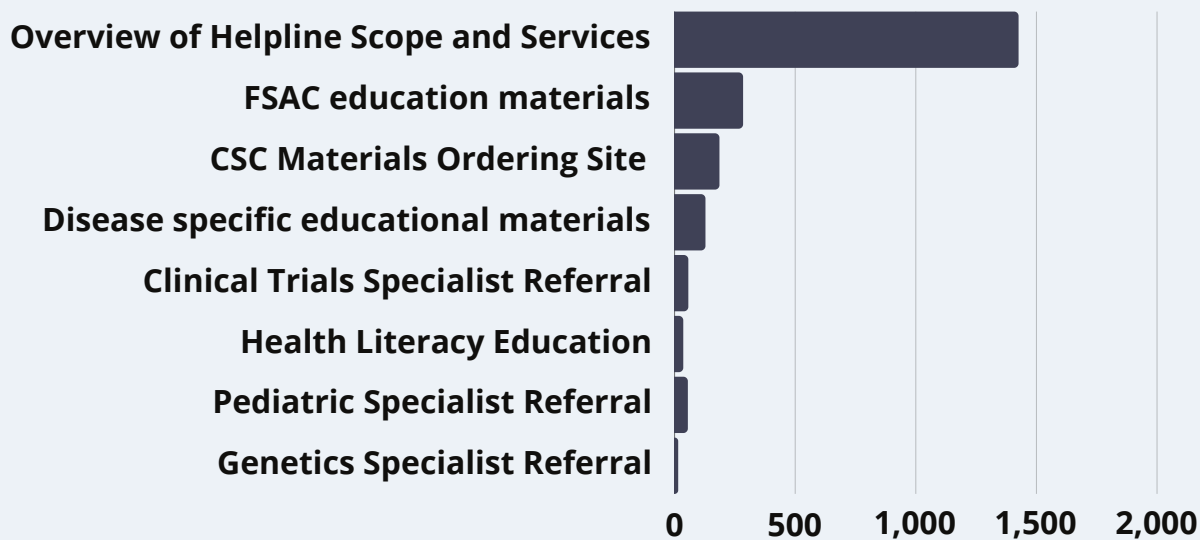


NAVIGATION INTERVENTIONS



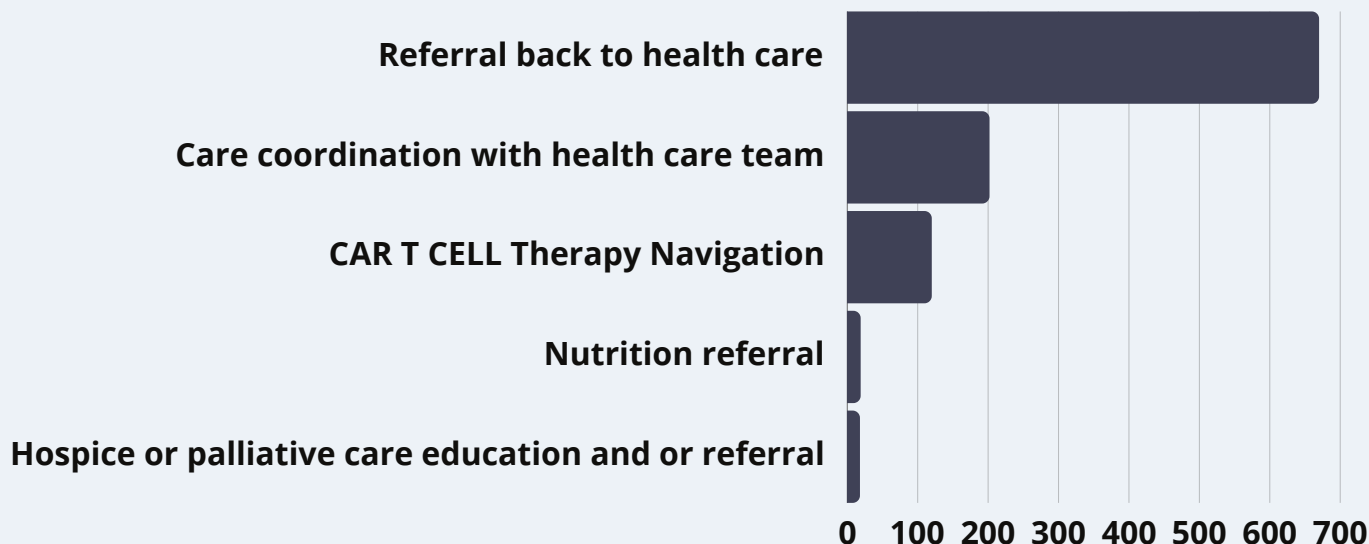
Education

Helpline navigators and specialists provided education on a variety of topics, including health literacy education and referrals to specialists. In total, **2,187** such interventions were completed.



Medical: Symptom Burden

Helpline navigators and specialists provided assistance in a variety of ways to assist callers who identified medical concerns. In total, **1,029** such interventions were completed.

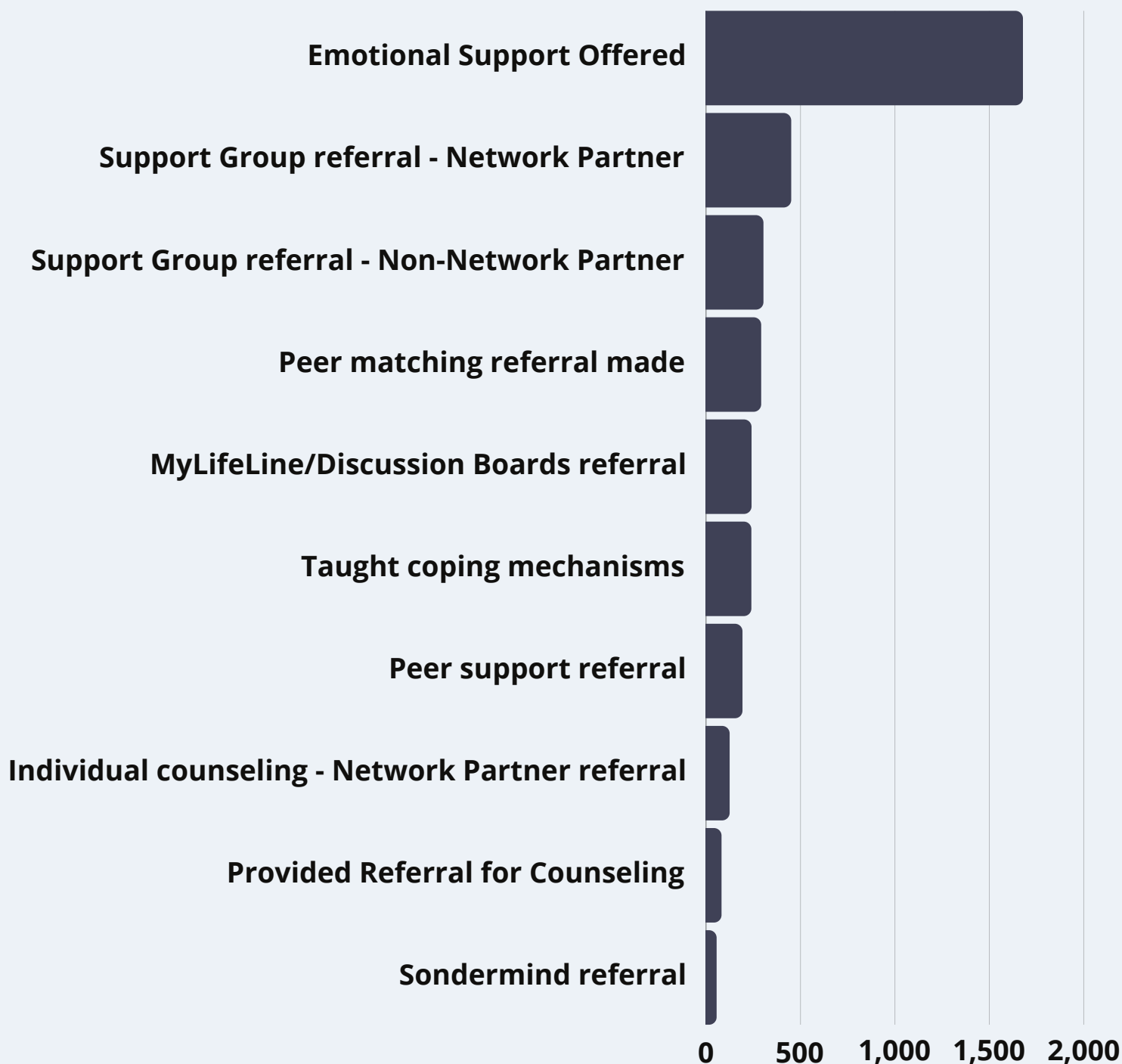


NAVIGATION INTERVENTIONS



Support

Helpline navigators and specialists provided support to callers in many ways, such as through referrals to network partner and community organizations and by providing education and support. In total, **3,662** such interventions were completed.



NAVIGATION INTERVENTIONS



Communication

Helpline navigators and specialists assisted callers with communication in many ways, such as re-connecting them with existing supports, helping them navigate the health care system, and providing treatment decision counseling support. In total, **1,178** such interventions were completed.

Referred to Existing Support

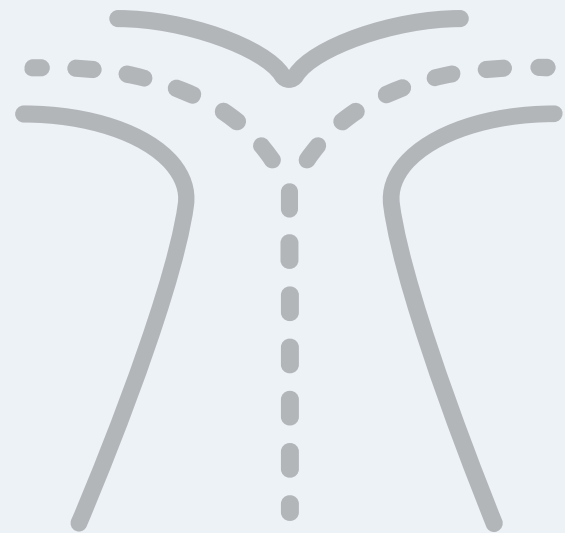
(544 callers) received this intervention

Education on "How To" Navigate the Health Care System and Communicate a Cancer Diagnosis

(411 Callers) received this intervention

Medical Translation Services Utilized or Translation by Helpline Staff

(96 Callers) received this intervention



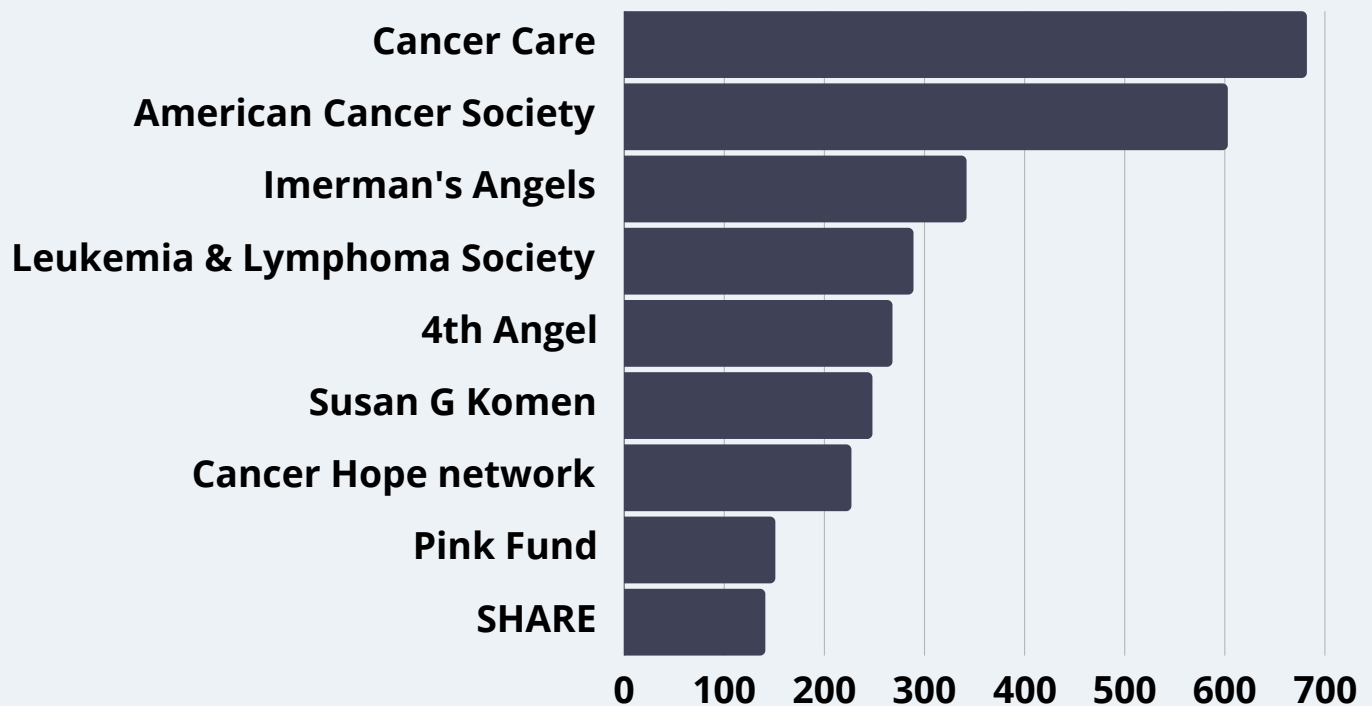
Open to Options Treatment Decision-Making Support

(112 Callers) were offered this intervention

(15 Callers) completed this intervention

NAVIGATION INTERVENTIONS

Referral to National Organizations



Top Referrals to Other National Organizations

Partners in Care	131
National Cancer Institute	109
Colorectal Cancer Alliance	99
Triage Cancer	75
Bone Marrow and Cancer Foundation	73
ZERO Cancer/ Us Too	65
Cancer and Careers	51
Open Arms Foundation	41
PanCan Network	40
International Waldenstrom's	5
Macroglobulinemia Foundation	

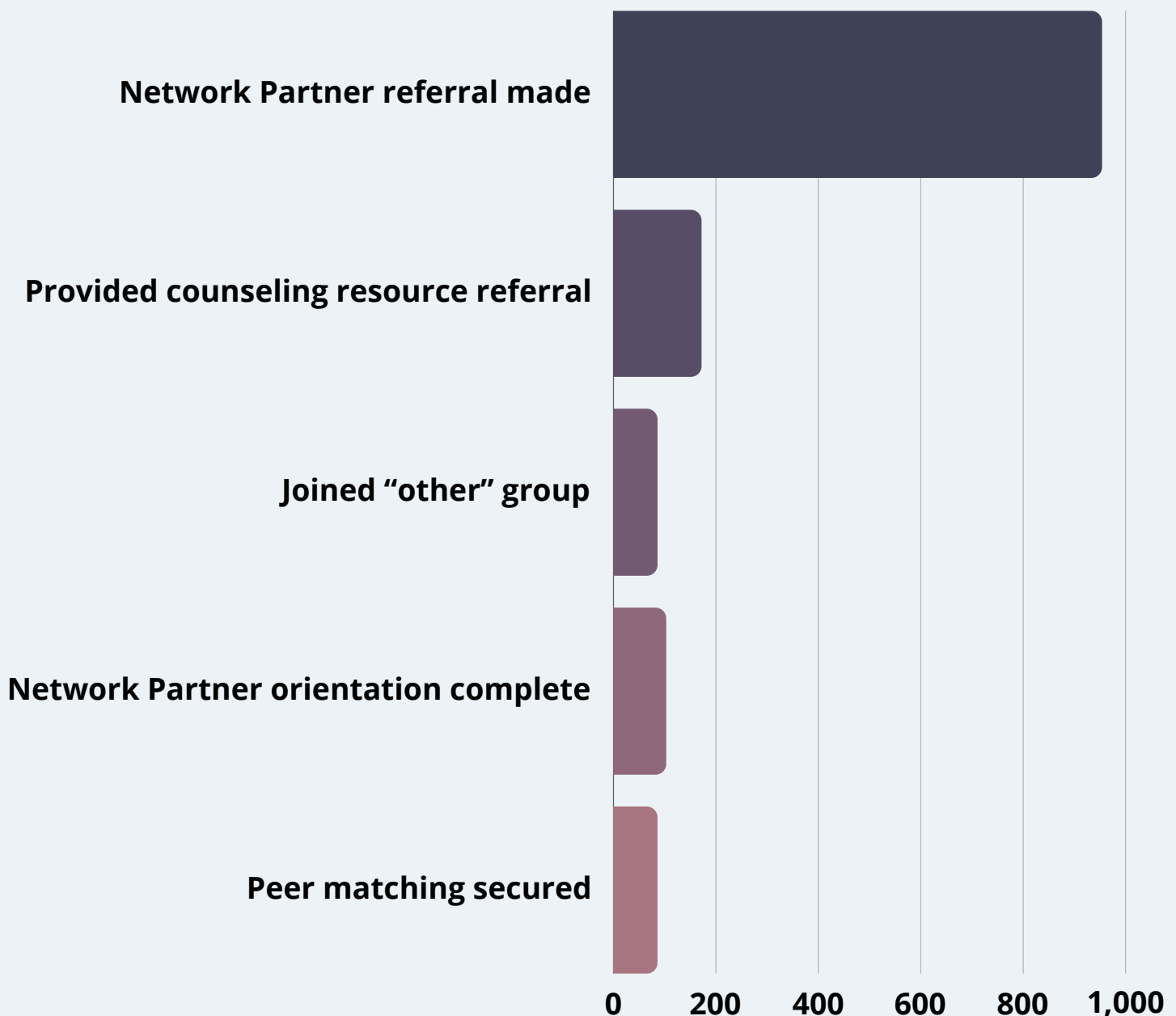
NAVIGATION OUTCOMES



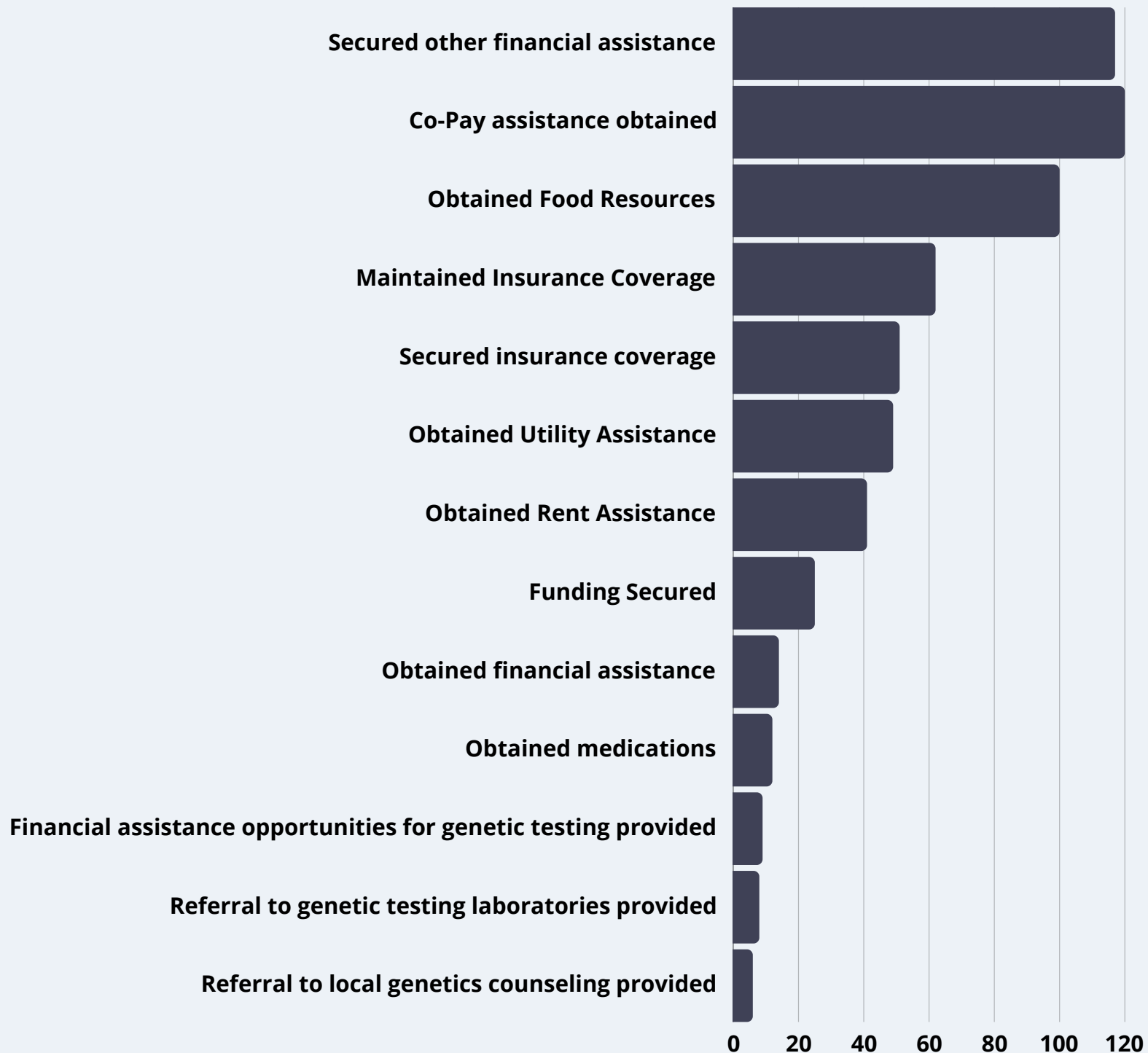
NAVIGATION OUTCOMES

Patient & Caregiver Support

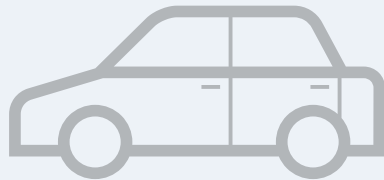
In February of 2022, with the implementation of our new, proactive navigation model, we began tracking caller outcomes in follow-up calls. The following outcomes are a result of CSC Helpline support.



NAVIGATION **OUTCOMES** (FINANCES)



TOP **SOCIAL DETERMINANTS** REPORTED BY CALLERS



Access to reliable Transportation



Adequate Health Literacy



Health Insurance



Enough food to eat

DEFINITIONS

Average call time- the average amount of time the HL staff spent on handled and outbound calls.

Average wait time- the average amount of time a person is placed on hold until a HL staff answers the call.

Community Navigator- a masters prepared, licensed mental health professional with background experience and training in oncology who provides distress screening and navigation to support patients and caregivers on the Cancer Support Helpline.

Communication with Physician- if caller is having difficulties communicating with their health care providers.

Coping with emotions- has 6 different categories see below for details and see graph on page 4.

Coping with emotions: Anxiety/Fear- if caller is experiencing fear and worry. For instance: "What if the treatment does not work. I can't sleep"

Coping with emotions: Bereavement/Grief- if caller is experiencing grief and loss.

Coping with emotions: Caregiving- if caregiver expresses emotional difficulty with caregiving roles

Coping with emotions: Depression/Sadness- if caller is dealing with sadness and/or depression

Coping with emotions: Newly Diagnosed- if caller is newly diagnosed and dealing with general stress associated with a new diagnosis

Coping with Mental Health Issues- if the caller is demonstrating some mental illness that is beyond the emotional response of their cancer diagnosis

Decision support- when caller is faced with different treatment options and needs help in making decisions (Open to Options)

DEFINITIONS CONT.

External Long Term Counseling Referral- if caller is experiencing mental health issues and seeks additional support. External (non CSC related) counseling needed during treatment.

External Long Term Counseling- if a caller is seeking external long term counseling.

Education/General Information- when a caller has a general cancer related question or needs knowledge on cancer.

Financial/Concrete Needs- if caller expresses concern about living expenses, income sources during and/or at the end of illness. Also, seeking lodging in different treatment center areas.

Financial/Health insurance- if caller has no insurance, copay problems, underinsured, non covered medical expenses.

Find a CSC- if caller wants to locate a CSC affiliate.

Helpline specialist referrals- the number of consults conducted by the specialists.

Handled Call- any call that comes in that gets answered.

Inbound Call- any call that comes in to the Helpline, either to our main 888 number or any of the partner numbers.

National Organization-if you provide someone with national resources.

Navigation Follow-up- if navigator provided navigation follow-up to caller.

Navigation Initial Contact- if navigator initiated first call with caller.

Network Partner- if a caller is seeking an affiliate in their area.

Outbound Call- a call made by the Helpline staff.

Other Side effect/Side effect management- if caller is seeking help re: side effects from treatment.

DEFINITIONS CONT.

Open to Options- if a caller is seeking tips for treatment decision making.

Psychosocial Educational Information- if caller is seeking psychosocial cancer related information. For instance: "The doctor gave me information but I would like to learn more." "Where can I get reliable information." "I worry about information on the internet".

Proactive Navigation One Session- for every call that requires emotional/psychosocial support.

Proactive Navigation Multiple Sessions- for callers who require multiple sessions for support.

Resource Specialist- an expert in cancer resources who navigates patients and caregivers on the Cancer Support Helpline.

Seeking Support- if caller is seeking group support, Peer to Peer, online, telephone or face to face support.

Support Group Referral- if caller is seeking a support group.

Transportation- if caller is seeking information regarding transportation.

Treatment Centers- if caller is seeking treatment centers.

Total Email Referrals- the number of email referrals that came in from partners.

Total Helpline activity- outbound, handled calls, chat, and email activity.

Total Chat- the number of chats that were handled.

Total Email Activity- number of emails received by the Helpline.

Transportation Resource- if a caller is seeking transportation resources and you are able to provide it to them.

Unique Calls/Callers- individuals who call the Helpline for the first time.



THANK
YOU



CANCER SUPPORT
COMMUNITY
CANCER SUPPORT HELPLINE
(888) 793-9355