

# State of the Survivor

# 2022

# A LETTER FROM THE CEO

Our 2022 State of the Burn Survivor Survey provides our community with a valuable opportunity to dive deep into a better understanding of the burns survivor and identify ways that we can better support our community. The study captures a range of perspectives to further understand how our organization can support our mission to advocate and support survivors physically, mentally, and emotionally.

Phoenix Society for Burn Survivors conducted this research to analyze and discover new ways of support and develop a plan to continue to perform this survey annually to understand performance at scale. It is important to note that this is our first attempt as an organization to gather information from our community to share with you, our community. We've gathered the information from various outlets, from promotional emails to our database and through promotional efforts on social media.

This survey helps us better advocate for the survivor from the moment the injury happens to the long-term effects it can have in every aspect of their lives. For a survivor, support and assistance can come in many forms—from the financial costs they incur, to the medical and emotional support around them, to the individuals in their lives who love and care for them. Our goal with this survey is to shed light on the trends in the industry so that as a community, we can come together to help provide better outcomes, and allow survivors to live healthier, happier lives.

Every year, 486,000 burn injuries require medical attention in the United States alone. While survival rates are high, living with a burn injury can be difficult in every aspect of life. Our 'State of Survivor' Survey is aimed at helping to continue to showcase gaps in care, support, and assistance to help with providing better outcomes for those we serve. Now, more than ever, we're asking for your support to help serve our population in the areas where they've identified a need for greater assistance.



Warm Regards,

A handwritten signature in black ink that reads "Amy Acton".

Amy Acton  
Chief Executive Officer  
Phoenix Society for Burn Survivors



Donate Today

# WHAT WE'VE LEARNED

## Common Survey Themes That Survivors Shared with Us



### **Mental Health is Important—and Necessary.**

68% of survivors agreed that the availability of mental health resources was one of the greatest areas of need. About 57% of survivors shared that in the last 12 months, they experienced difficulty with mental health, but 4 in 10 survivors don't receive the support they need.



### **Survivors' Top Concerns May Surprise You.**

We asked survivors to select areas that were of most concern to them. While managing side effects is widely known as a great area of concern for survivors—getting enough exercise and maintaining a healthy weight were ranked as top areas of concern for the community, even above the costs of medical care and financial support.



### **Experiences Vary Based on Time from Injury, Burn Injury Type, and More.**

Our results validated what we already concluded—that survivors less than 5-years post-injury face a lot of experiences related to their burn injuries. Specifically, side effects such as skin irritation or itchiness, difficulty with temperature regulation, tightened skin, sleeplessness, discomfort in social or relationship interactions, and further—have much more burn-related reconstruction. In addition, difficulties or experiences varied for a variety of factors—no survivor is the same, and support may need to be customized based on how a survivor may identify.



### **Support Preferences Vary—New Opportunities Presented.**

We learned that support preferences vary—and many survivors aren't connected at all. We were surprised to learn that more than half of the survivors surveyed prefer to use social media to gain support. In addition, only 8% of survivors who are four years or less post-injury reported an ability to gain support in person. Support looks different for different survivors—specifically those with newer injuries—who prefer to observe and read before diving into a community-driven conversation. We were also surprised to learn that while 5 out of 10 survivors prefer to give back by donating time through volunteering for Phoenix SOAR, only 2 out of 10 survivors have done so in the last 12 months.



### **Giving Back Means Something Different to Everyone.**

The power of sharing stories as burn survivors is important—in fact, 72% of survivors prefer to give back by telling their own stories. We learned that 57% of survivors are looking for ways to give back after a burn injury, and 'giving back' means something different to each survivor. With lots of ways to give back from monetary donations to peer support—survivors have varying preferences on giving back. Survivors with a higher percentage of burns prefer to share their stories while survivors with lower percentage of burns prefer to volunteer, and support through peer-to-peer opportunities.



### **Survivorship Changes with Time**

When asking survivors to rate how they feel about using the term 'survivor' to reference themselves on a scale from 1 to 100—the results showed that the average response for participants was an 87. However, when analyzing how they felt with this term based on years from injury, we learned that the overall sentiment with survivor took a turn within the first five years of an injury before finding more affinity to the term after 5 years.



### **Level of Care Needs Improvement**

The life-long impact of a burn injury is evident—but the care related to the injury itself is not lasting. While 65% of survivors rated their care after a burn injury as excellent, only 33% of survivors rated their current care as excellent. Further, evidence of disparities exists—survivors identifying as a person of color rated care lower than those identifying as white. Survivors with abuse or attack-related injuries rated their care significantly lower than those with fire or other related injuries.

# ADVOCATING FOR THE SURVIVOR

We asked the survivors to select the areas where they believe burn survivors need the most support. We've placed the top areas each group voted for in the information below.

**68%**

Overall highest area of support needed from the community was the "availability of mental health resources."

**59%**

Ranked "burn survivors & the media: changing the portrayal of the survivor" as a top need for support.

**58%**

Survivors ranked "education for the healthcare industry about the burn survivor" as a great need for support.



Hidden Burn Survivors



Facial Burn Survivors



Child Burn Survivors



Amputee Burn Survivors



Male Burn Survivors



Female Burn Survivors



Under 35



Over 65 Burn Survivors



TBSA Greater than 60%



TBSA Less than 60%



Burn Injury 10+ Years Ago



Burn Injury Less than 5 Years Ago



Annual Household Income Less Than 30K/Year



Annual Household Income Greater Than 75K/Year



Identifies as a Person of Color



Fire Related Burn Injury



Advocacy for the burn survivor journey.



Availability of opportunities to connect with other survivors.



Employment opportunities for burn survivors.

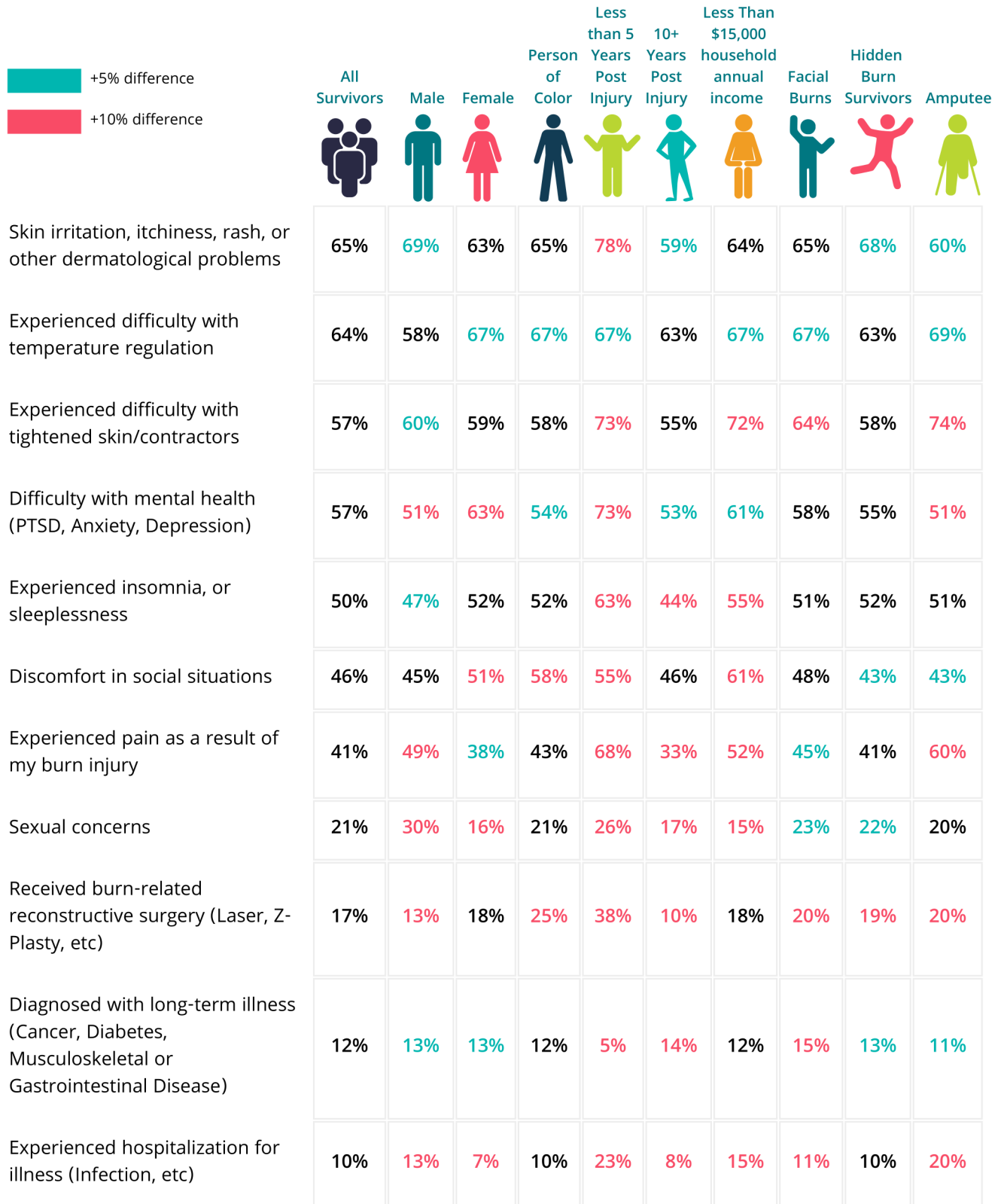


Availability of financial resources.



# SURVIVOR EXPERIENCES

We asked survivors which of the following they experienced in the last 12 months. Most notably, survivors less than five years post injury saw significantly more symptoms and experienced more concerns than group averages.



# SUPPORT AVAILABLE

We asked the survivors to select the areas where they currently connect with their community. Here is how they prefer to connect and engage with one another.

## How do you currently connect?



**55%**

prefer to connect through an online social media community.



**40%**

of male burn survivors aren't connected right now.



**36%**

of survivors 1-4 years post injury are connecting through online virtual support groups.

**67%**



of those younger than 35 years old prefer to connect through an online social media community.



**42%**

of those older than 55 prefer to connect through an online social media community.



**33%** of all survivors surveyed are not connected at all.



**8%**

of survivors who are 4 years or less post injury are connecting through in-person support groups.



**43%**

of burn survivors less than 1 year post injury are connecting with the community through resource articles and survivor stories.

# SUPPORT AVAILABLE

We asked survivors about their engagement with Phoenix Society for Burn Survivors in the last 12 months.



**27%**

have attended a Phoenix Society Virtual Support Group by video chat or online peer support group.



2 in 10 survivors **attended** a non-support-focused virtual event gathering.



1 in 10 survivors **received** support from a Phoenix SOAR Peer Supporter.



**62%**

who attend virtual support groups prefer to attend quarterly or annually.



2 in 10 survivors **gave** support as a Phoenix SOAR Peer Supporter.



**33%**

Connect by reading Phoenix Society's Journey Magazine



**28%**

Connect by reading Phoenix Society's Monthly Email Newsletter

# SUPPORT AVAILABLE

We asked survivors to rate the various types of support they did receive during their journey. Support comes in many forms—from financial or legal to mental health and medical.

In the last 12 months, how often did you...

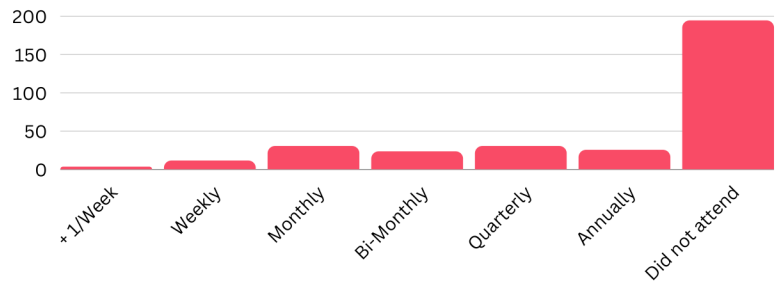
## All Burn Survivors



85%

did not attend an in-person support group.

### Attended virtual peer support (video or online chat)?



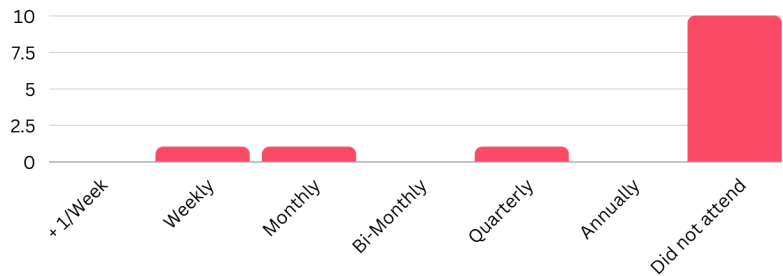
## Less Than 1 Year Post Injury



92%

did not attend an in-person support group.

### Attended virtual peer support (video or online chat)?



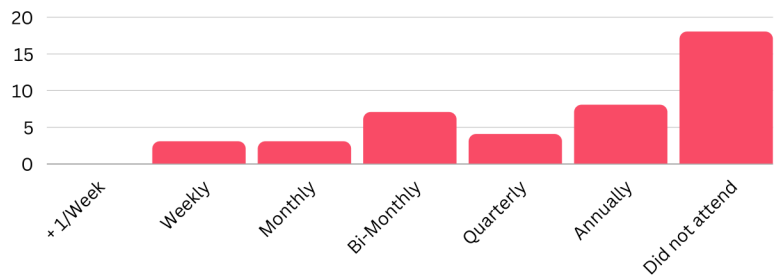
## 1-4 Years Post Burn Injury



92%

did not attend an in-person support group.

### Attended virtual peer support (video or online chat)?



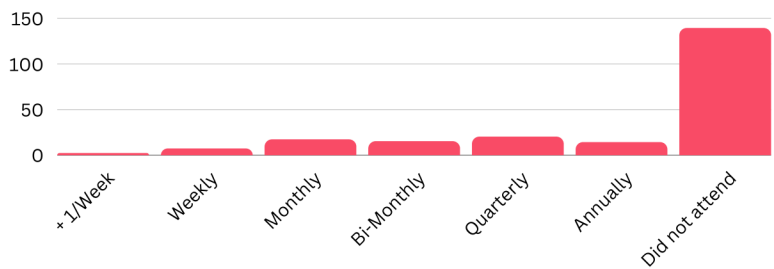
## 10+ years post burn



85%

did not attend an in-person support group.

### Attended virtual peer support (video or online chat)?



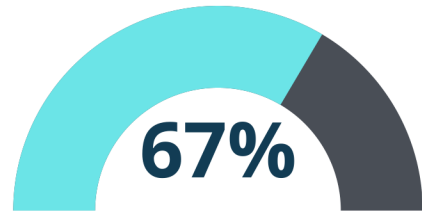
# SUPPORT OPPORTUNITIES

We asked survivors to rate the various types of support they did receive during their journey. Support comes in many forms—from financial or legal to mental health and medical.



**68%**

of survivors reported no support from legal counsel.



**67%**

of survivors rate care from doctors and healthcare teams as above-average care.



**62%**

of survivors reported no support from financial counsel.



4 in every 10 survivors surveyed receive no support from a mental health professional.



## Have Concerns About Gaining Employment (16% Average)

- 30% Amputee Burn Survivors
- 17% Facial Burn Survivors
- 13% Hidden Burn Survivors
- 11% Child Burn Survivors



## Have Concerns About Receiving the Proper Medical Care (23% Average)

- 36% Amputee Burn Survivors
- 28% Facial Burn Survivors
- 26% Child Burn Survivors
- 20% Hidden Burn Survivors



## Have Concerns About Getting Enough Exercise (35% Average)

- 47% Amputee Burn Survivors
- 36% Hidden Burn Survivors
- 35% Facial Burn Survivors
- 23% Child Burn Survivors



## Have Concerns About the Uncertainty of the Future (31% Average)

- 47% Amputee Burn Survivors
- 34% Facial Burn Survivors
- 31% Hidden Burn Survivors
- 20% Child Burn Survivors



## Have Concerns About Getting Support from Family and Friends (18% Average)

- 19% Facial Burn Survivors
- 19% Hidden Burn Survivors
- 19% Amputee Burn Survivors
- 17% Child Burn Survivors

# SURVIVOR CONCERNS

We asked survivors to share which of the list provided were of top concern for them. Here are the results by Total Body Surface Area (TBSA) of a burn injury.

TOTAL BODY SURFACE AREA (TBSA) OF BURN INJURY

Concern	All	0-20%	21-40%	41-60%	61-80%	80%+
Managing Side Effects	<b>53%</b>	47%	58%	49%	55%	56%
Maintaining a Healthy Weight	<b>40%</b>	31%	43%	37%	51%	28%
Getting Enough Exercise	<b>35%</b>	35%	32%	37%	39%	33%
Cost of Medical Care	<b>31%</b>	29%	37%	24%	31%	33%
Managing a Proper Diet	<b>31%</b>	29%	25%	33%	41%	28%
Uncertainty of the Future	<b>31%</b>	35%	29%	28%	33%	33%
Having Financial Support	<b>32%</b>	20%	32%	27%	41%	39%
Being Able to Support Family and Friends	<b>25%</b>	22%	22%	29%	31%	22%
Receiving Proper Medical Care	<b>23%</b>	22%	13%	24%	33%	33%
Cost of Prescriptions and Treatment	<b>18%</b>	12%	18%	20%	18%	28%
Receiving Support from Family & Friends	<b>18%</b>	22%	16%	13%	25%	17%
Gaining an Increased Mobility	<b>17%</b>	10%	13%	16%	29%	33%
Gaining Employment	<b>16%</b>	14%	16%	9%	25%	22%
Making Progress in Physical or Occupational Therapy	<b>13%</b>	12%	10%	13%	18%	11%
Social Acceptance & Relationship Building	<b>5%</b>	4%	5%	2%	8%	5%
Long-Term Affects of a Burn Injury	<b>3%</b>	0%	4%	2%	0%	11%

+10% difference



# SURVIVORSHIP

When asked to rate how they feel about using the term survivor on a scale of 1-100, the average response of participants is 87.



How well does the term  
'Survivor' resonate with you?

## How well do you identify with the term 'Survivor'?

On a scale from 1-100, average scores.

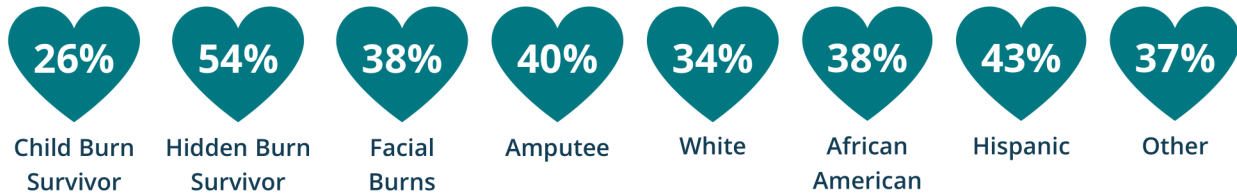




# SUPPORT

Survivors share how they would rate the level of support they received for their burn injury.

## Respondents Who Rated The Support They Currently Receive As Excellent\*



## Percentage of Survivors Who Rated Current Support As Excellent (By Time From Injury)



**52%**

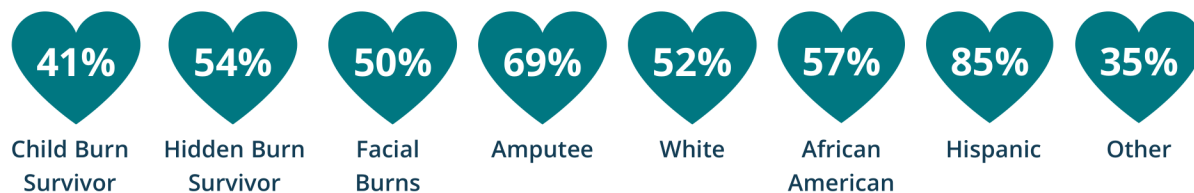
of survivors rate their support immediately following a burn injury as excellent.



**35%**

of all survivors rate their current support for a burn injury as excellent.

## Percent of Survivors Who Rated Support As Excellent Immediately After Burn Injury\*\*



## Percent of Survivors Who Rated Support As Excellent Immediately After a Burn Injury (By Time From Injury)\*\*

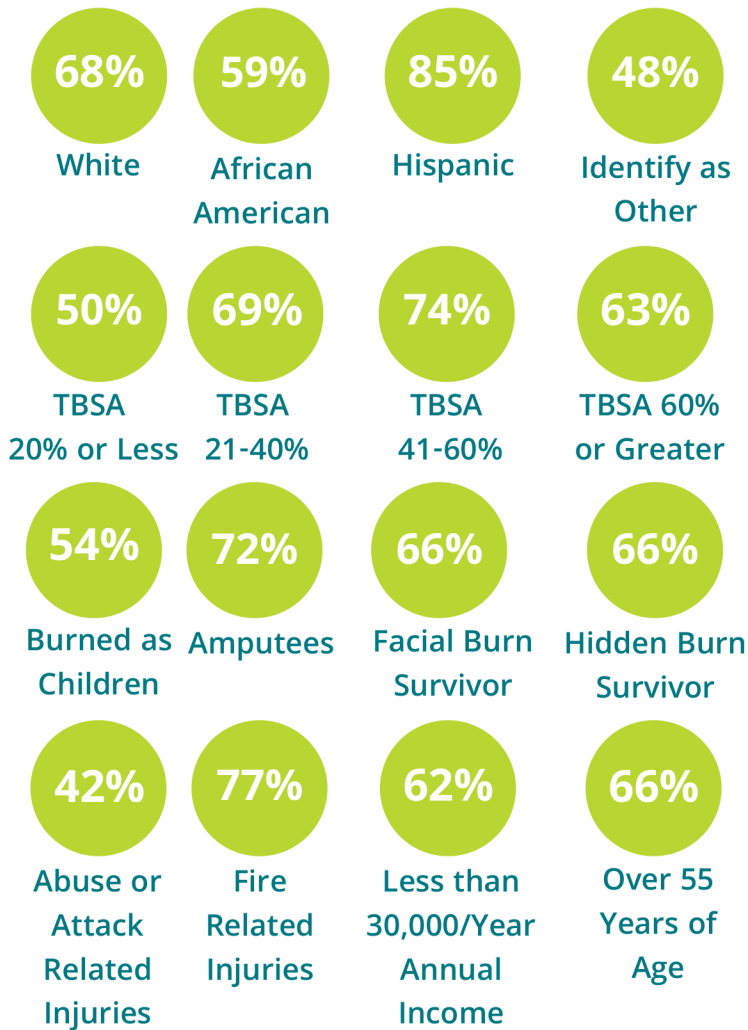


\*Regardless of time from injury \*\*Within 1 Year

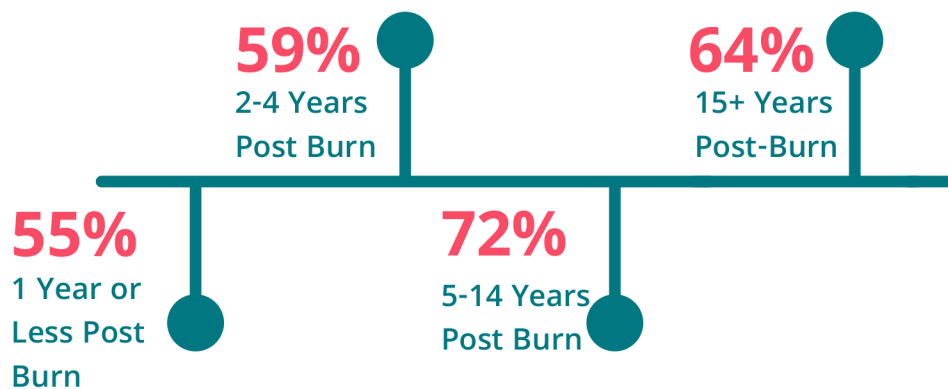
# IMMEDIATE LEVEL OF CARE

Survivors share how they would rate the level of care they received for their burn injury. This is regardless of the time a burn survivor is from an injury.

## Percentage of Survivors That Rate The Care They Received Immediately Following Injury As Excellent



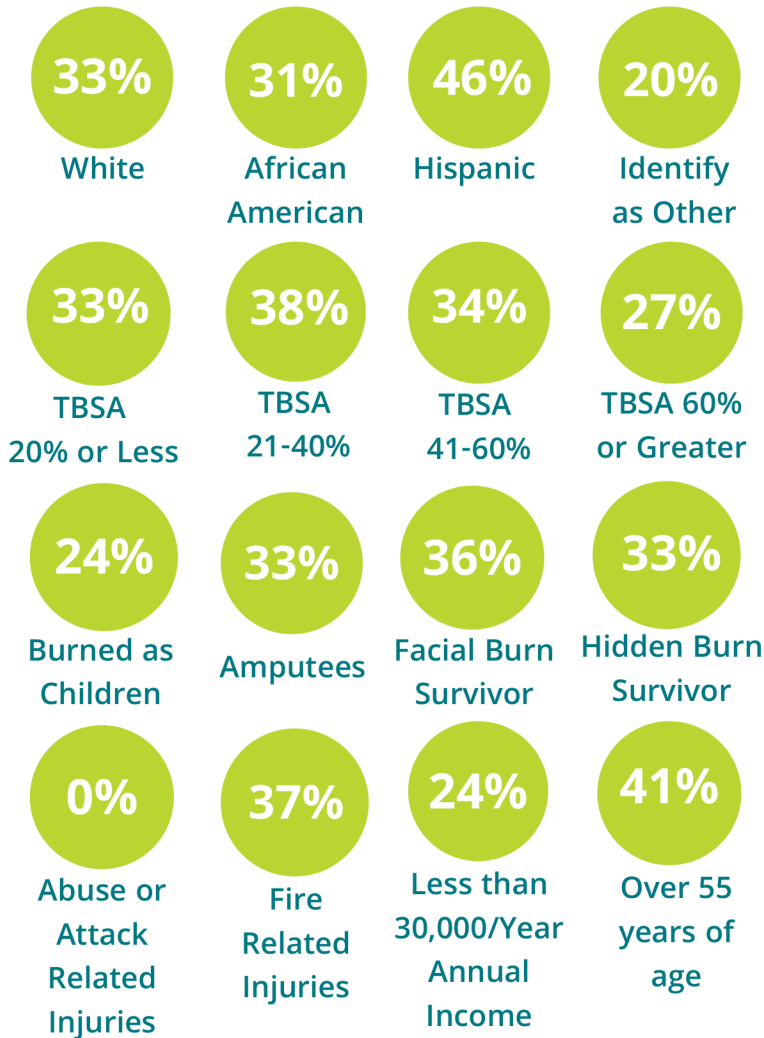
## Rated Their Care 1-Year Post Injury as excellent by time from injury



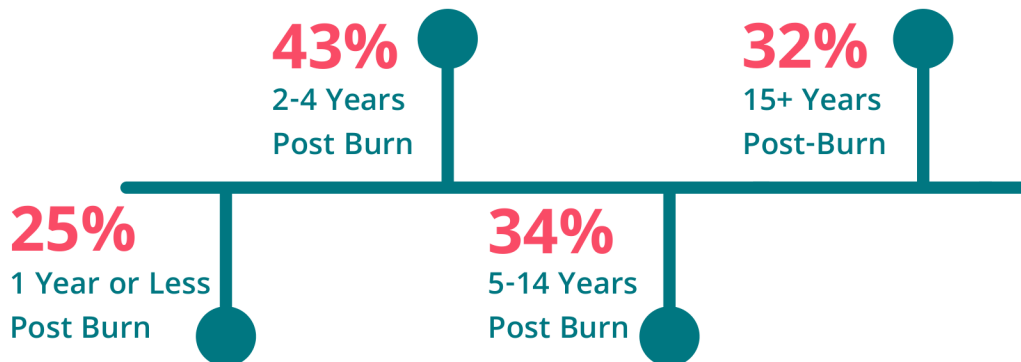
# CURRENT LEVEL OF CARE

Survivors share how they would rate the current level of care they receive for their burn injury. This is regardless of the time a burn survivor is from an injury.

## Percentage of Survivors Rating Their Current Care As Excellent



## Rated Their Current Care as Excellent by Current Years from Injury



# GIVING BACK

We asked our community to share motivators behind giving back and identified trends in our community's current methods of giving.



**72%**

prefer to give back by telling the story of how their burn injury occurred.



**57%**

prefer to give back by joining a peer support group or Facebook group to connect with others.



**74%**

of survivors believe that having a personal connection to the cause was the primary reason to decide to give back.



**41%**

of females prefer to give back by providing advice in a Facebook group versus the 27% of males that prefer this method.



**57%**

of survivors are looking for opportunities to give back to the community.



5 out of 10 survivors prefer to give back by volunteering through Phoenix SOAR or donating time to nonprofits.



2 out of 10 survivors have given back in the last 12 months by providing support through Phoenix SOAR.



# RESPONSE DEMOGRAPHICS

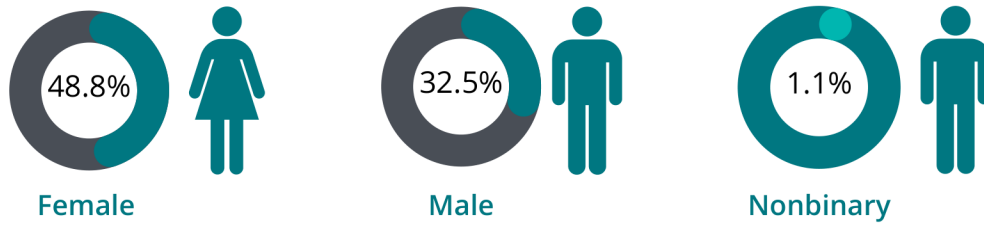
# 369

 Burn Survivor Respondents

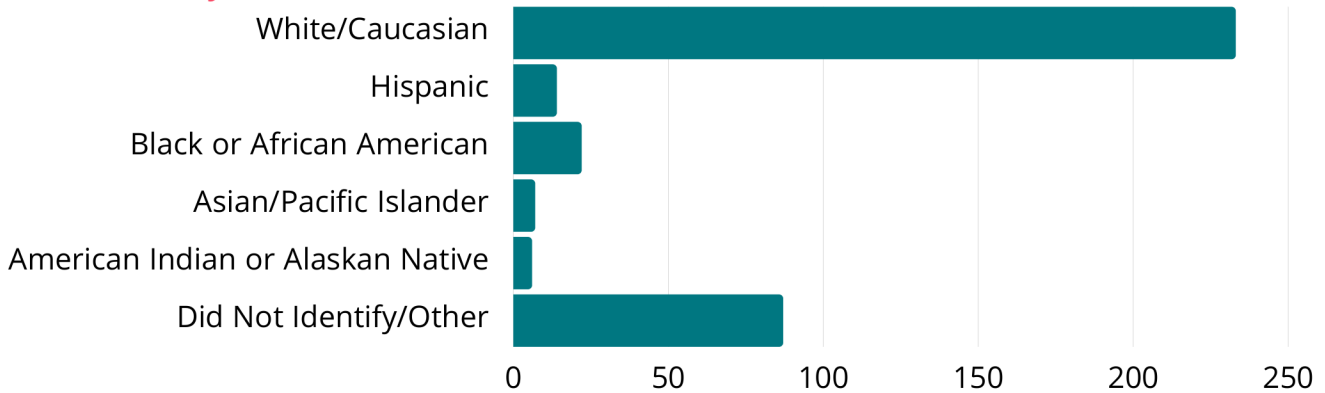
We collected survey responses from our burn community through our database and social media outreach.

## Gender

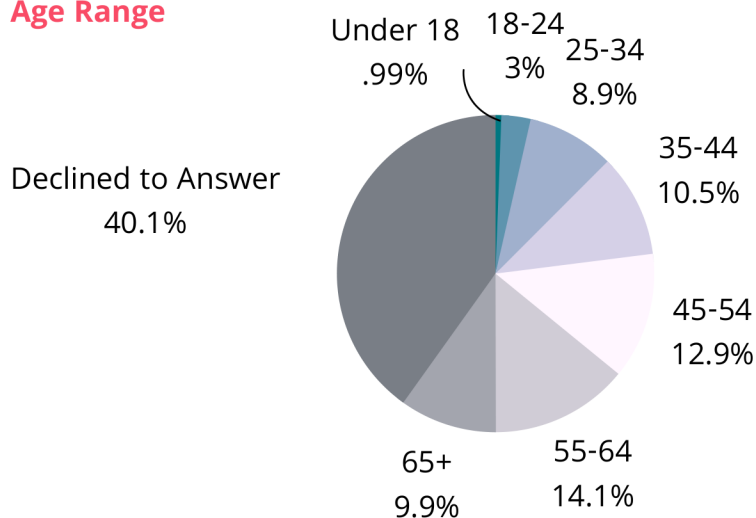
Did Not Answer: 18%



## Racial Identity



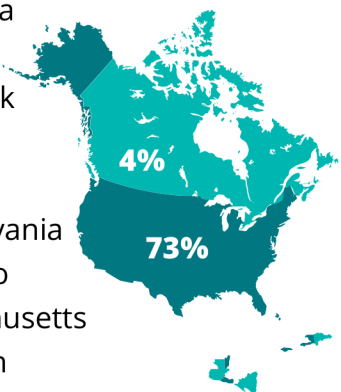
## Age Range



## Responding Locations

### Top States

1. California
2. Florida
3. New York
4. Texas
5. Ohio
6. Pennsylvania
7. Colorado
8. Massachusetts
9. Michigan
10. Tennessee



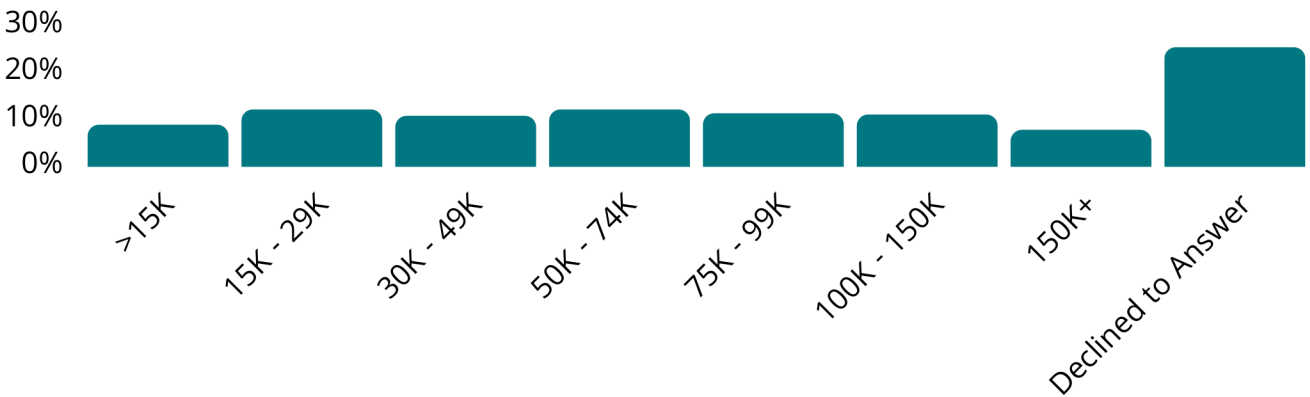
# RESPONSE DEMOGRAPHICS

# 369

Burn Survivor  
Respondents

We asked the burn community to self-identify and share with us (optional) details about their burn injury.

## Household Income Level



1 in 10 survivors are amputees.



5 in 10 survivors surveyed identify as having facial burns

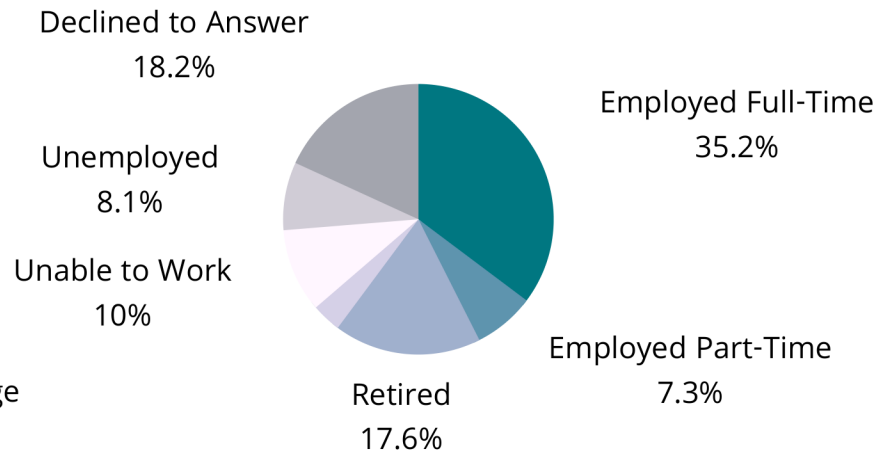


3 in 10 survivors were burned as a child.



7 in 10 survivors identify as hidden burn survivors

## Employment Status



- 86% Attended Some College
- 58% Achieved A Degree
- 17% Did Not Answer

# RESPONSE DEMOGRAPHICS

# 369

Burn Survivor  
Respondents

We asked the burn community to self-identify and share with us (optional) details about their burn injury.

