



TBI Waiver Update to Brain Injury Advisory Council

May 8, 2025

Purpose of the NC TBI Waiver

- Designed to provide rehabilitative services and supports that facilitate recovery and promotes choice, independence and community involvement for individuals with a traumatic brain injury either in or at risk of placement in institutional settings

Purpose of the NC TBI Waiver

- Goals include:
 - Value and support waiver beneficiaries to be fully functioning members of their community
 - Promote rehabilitation through evidence-based practices, and promising practices that result in real life outcomes for beneficiaries
 - Offer person-centered service options that will facilitate each beneficiary's ability to live in homes of their choice, have employment or engage in a purposeful day of their choice and achieve their life goals

Timeline

- The NC TBI Waiver approved to begin May 1, 2018
- Alliance selected by the State to administer the three-year TBI Waiver pilot
- Alliance began operation of the waiver in fall 2018 in Cumberland, Durham, Johnston, and Wake counties
- Waiver renewed for five years in April 2022
- Mecklenburg and Orange counties added in April 2023
- Harnett County added in July 2024

Areas of Eligibility

- Diagnostic eligibility
 - Requires establishing the presence and age of a TBI through medical records
- Level of care
 - Individuals must meet one of the levels of care described in the NC TBI Waiver application: Skilled Nursing or specialty (neurobehavioral) hospital
- Financial/Medicaid eligibility
 - Individuals must qualify for long-term Medicaid

Early Challenges

- Identifying individuals with TBI
 - Alliance searched data from claims and the call center, amongst others and completed community outreach to identify potentially eligible people in the community
- Age barriers
 - Initial waiver requirement of having sustained a TBI on or after age 22 excluded some of the highest-risk years for people to experience a TBI (ages 18-21)
- TBI vs non-TBI
 - Alliance had to help stakeholders to understand whether particular injuries were considered a TBI

Challenges

- Providers with TBI Expertise
 - Alliance had to recruit providers that were less familiar with Medicaid managed care as well and build capacity among existing providers
- Establishing diagnostic eligibility for individuals
 - Records for individuals with older injuries were difficult to obtain to validate TBI and age of injury
- Testing verifying LOC
 - No standard evaluation or test correlates directly to the TBI Waiver levels of care, so synthesis of multiple reports and evaluations is required to determine eligibility

Challenges

- Financial barriers
 - Many individuals that have experienced a TBI have financial barriers to Medicaid eligibility, either by having paid into disability in previous employment, a settlement from the injury, or other circumstances
- Understanding of the waiver
 - Individuals and their supports are often new to Medicaid, managed care, and social services, resulting in difficulty navigating the system and knowing what is available and what is not

TBI Interest Registry vs RUN

- TBI Interest Registry is a first-come, first served list of people that have contacted Alliance about possible participation in the TBI Waiver
- Waiver eligibility is not established for individuals on the Interest Registry
- Waiver enrollment is processed as individuals are able to establish clinical eligibility rather than original call date

Waiver Changes

- Age of injury adjusted from 22 and up in the original waiver to 18 and up upon renewal
- Allowance for individuals to qualify for Medicaid at 300% FPL under the waiver as opposed to 100% FPL in original waiver
- Supported Living service was added to the waiver at renewal
- Alliance developed a process for establishing TBI diagnostic eligibility when original records are not available
- Alliance partnered with a provider to establish an enhanced TBI group home

Waiver Enrollment by Waiver Year

Year	SNF Available	SNF Enrolled	Hospital Available	Hospital Enrolled	Total Enrolled	Termination	Total Slots Available	% of Allocation Filled
Pilot Year 1 (5/1/2018-4/30/2019)	44	12	5	0	12	0	49	24%
Pilot Year 2 (5/1/2019-4/30/2020)	89	18	10	2	20	1	99	20%
Pilot Year 3 (5/1/2020-3/31/2022)	95	25	12	2	27	10	107	25%
Renewal Year 1 (4/1/2022-3/31/2023)	95	56	12	3	59	6	107	55%
Renewal Year 2 (4/1/23-3/31/24)	95	68	12	5	73	6	107	68%
Renewal Year 3 (4/1/24-3/31/25)	95	72	12	8	80	8	107	82%

Termination Data

- 31 beneficiaries have left the waiver between December 2019 and March 2025
 - 8 passed away
 - 6 moved into different levels of care (Skilled Nursing, CAP/DA)
 - 6 moved out of the catchment
 - 6 opted to discontinue waiver services
 - 3 did not utilize services
 - 2 lost Medicaid after enrollment

Service Utilization

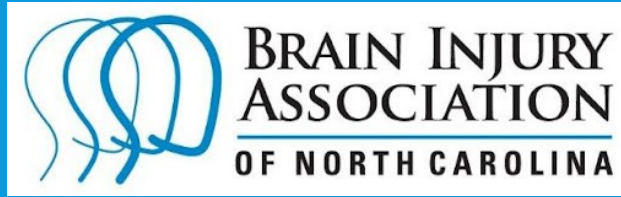
- Residential supports vs. in-home supports
 - 27 individuals using residential supports in group homes or AFLs
 - 53 individuals reside in a private home on their own or with family
- Meaningful day options
 - 26 individuals using Community Networking
 - 24 individuals using Day Supports
 - 23 individuals using Life Skills Training
- Specialized services
 - 54 individuals using Specialized Consultative Services
 - 20 individuals using Cognitive Rehabilitation

Non-waiver TBI Supports

- Individuals with TBI prior to age 22 qualify for I/DD services such as the Innovations Waiver or long-term Community Supports
- 1915i Supported Employment, Respite and Community Living and Supports available to people with TBI across age groups
- State-funded service definitions such as Community Living and Supports, Residential Supports, and Supported Employment updated in the last couple years to include TBI

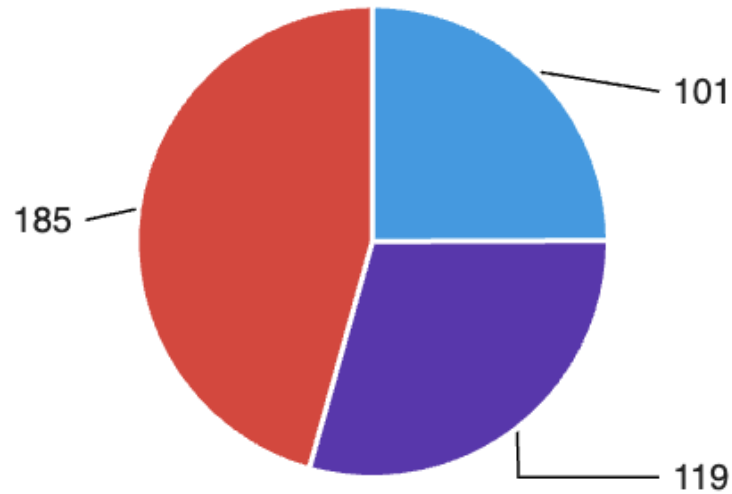
A Success Story





NEEDS AND GAPS SURVEY 2025

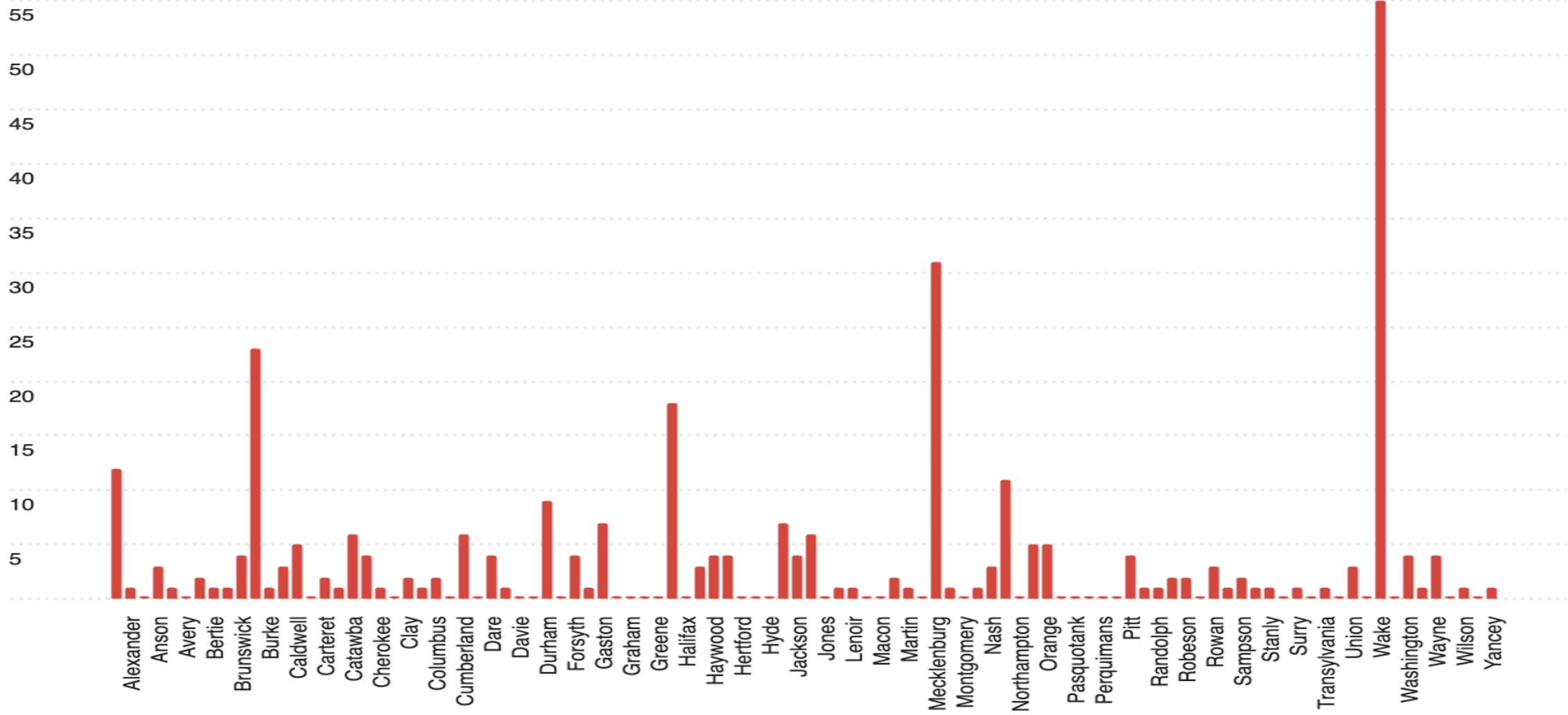
Preliminary Quantitative Results



■ I am the caregiver of a person living with a brain injury
 ■ I am a family member of a person living with a brain injury
 ■ I am a person living with a brain injury

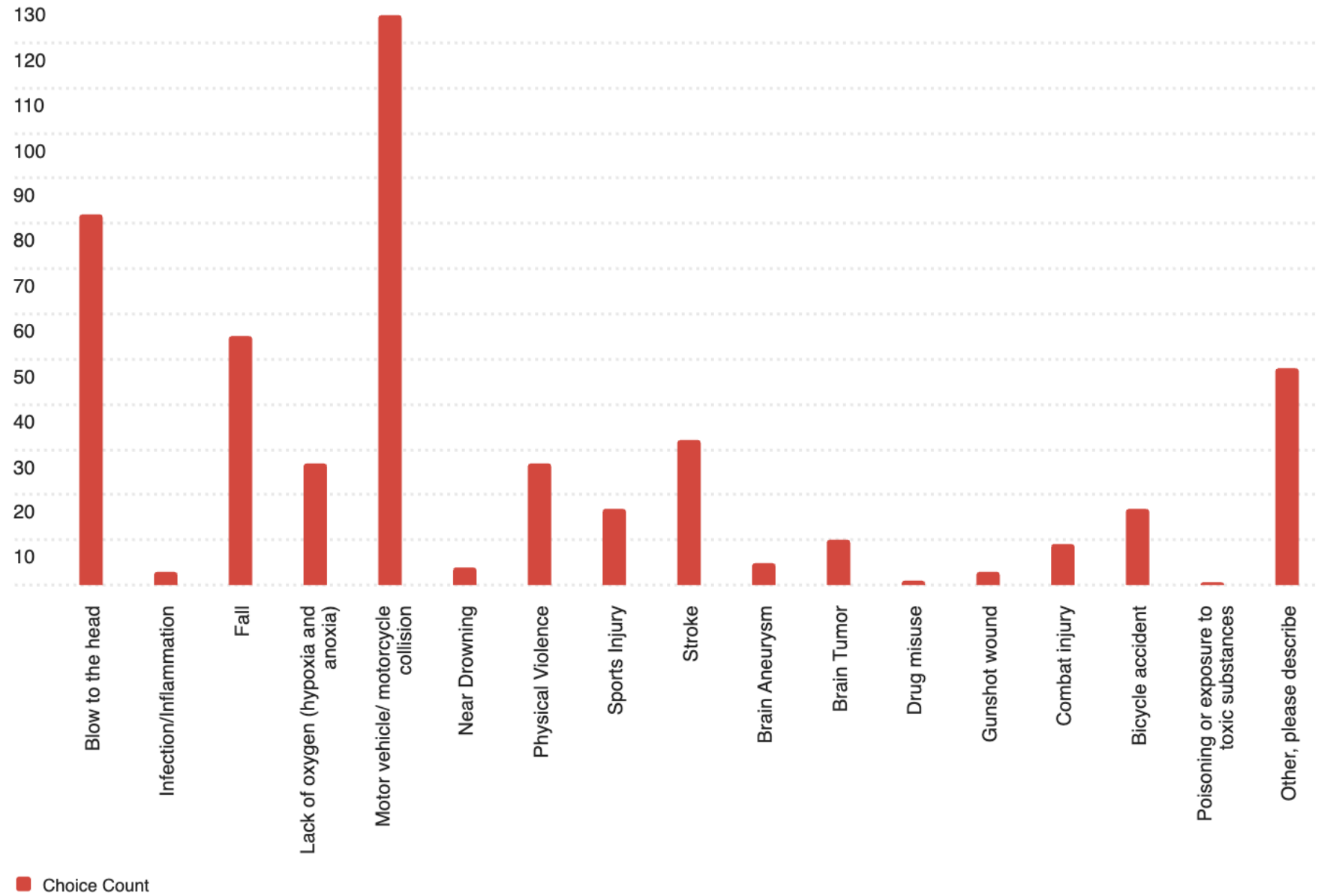
Person Taking Survey	Count
I am a person living with a brain injury	173
I am a family member of a person living with a brain injury	80
I am the caregiver of a person living with a brain injury	61
I am a family member of a person living with a brain injury, I am the caregiver of a person living with a brain injury	30
I am a person living with a brain injury, I am a family member of a person living with a brain injury, I am the caregiver of a person living with a brain injury	7
I am a person living with a brain injury, I am the caregiver of a person living with a brain injury	3
I am a person living with a brain injury, I am a family member of a person living with a brain injury	2
Grand Total	356

Q2 - What NC county do you (person living with a brain injury) currently live in?

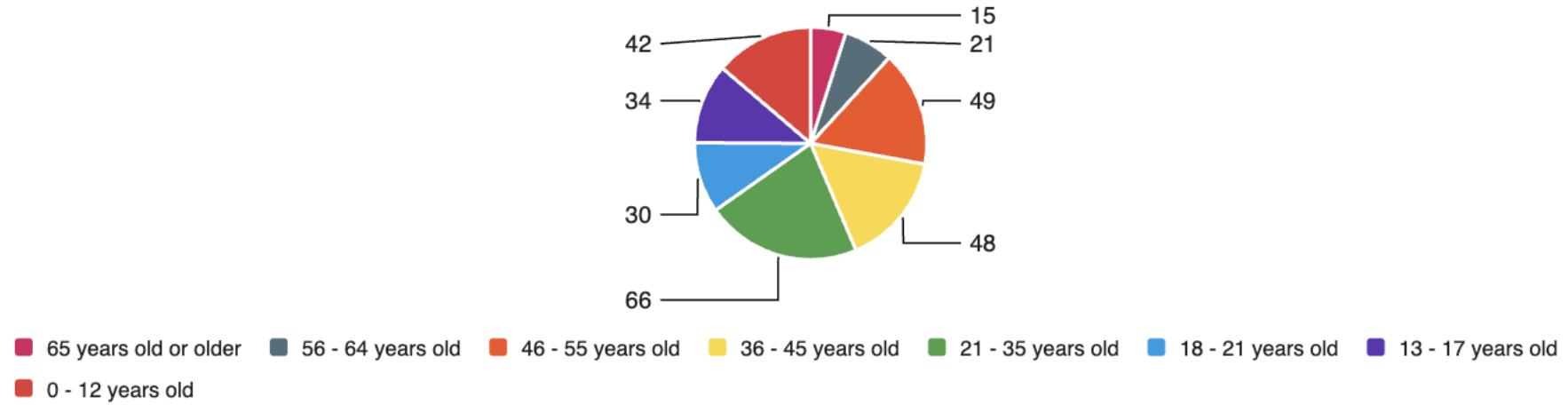


Choice Count

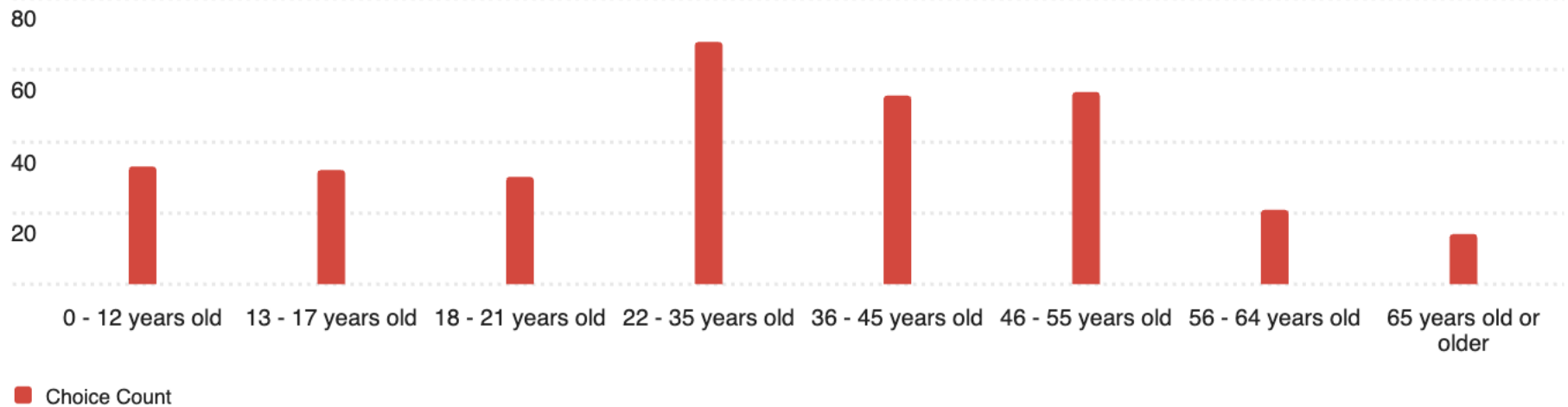
Q3 - What caused your brain injury? (check all that apply) - Selected Choice



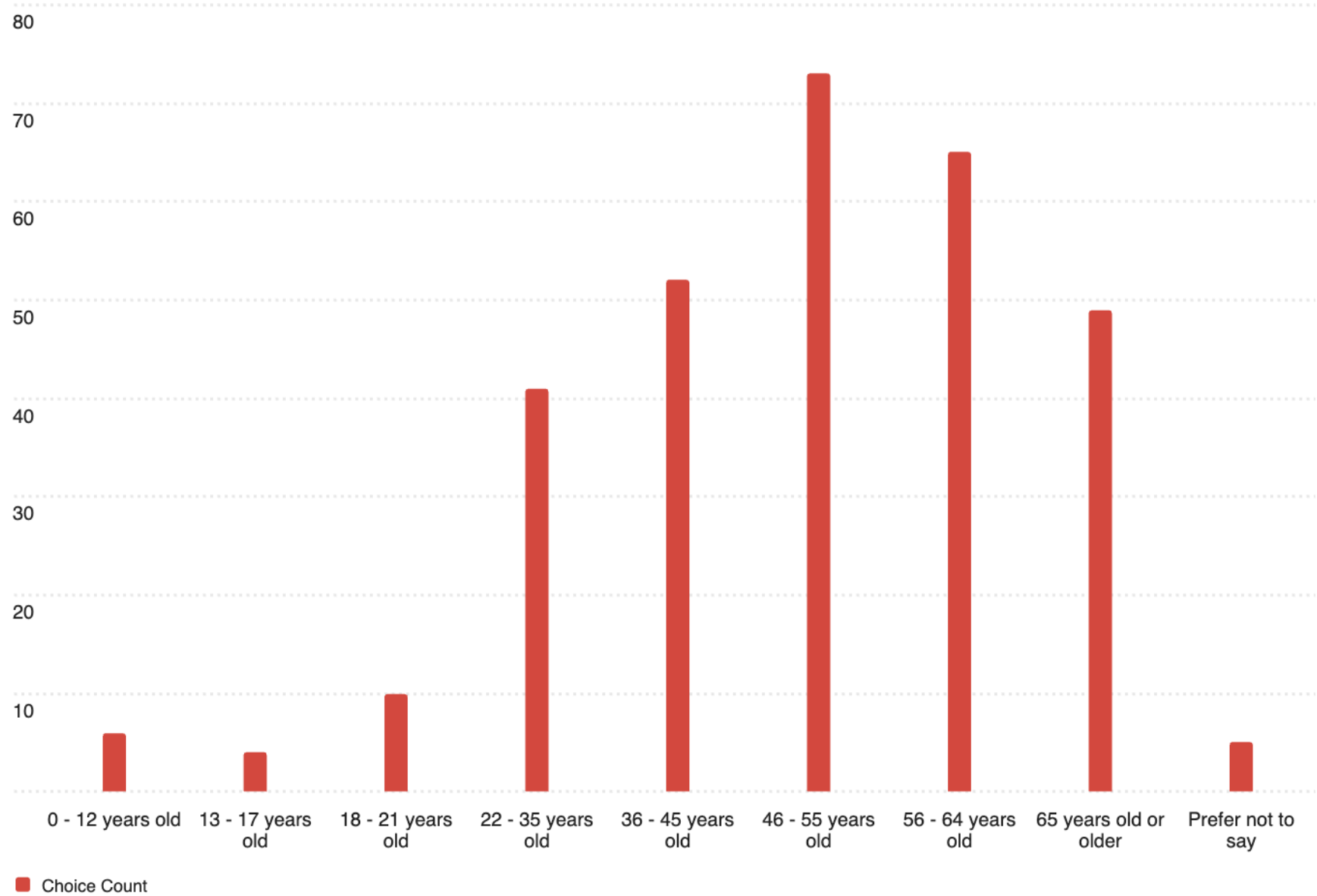
Q4a - What age was your brain injury sustained?



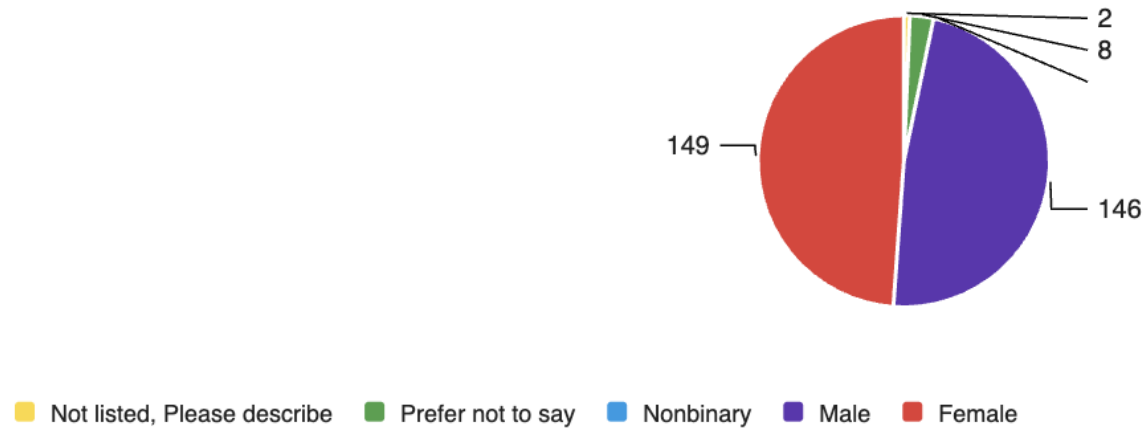
Q4b - What age was your brain injury diagnosed?



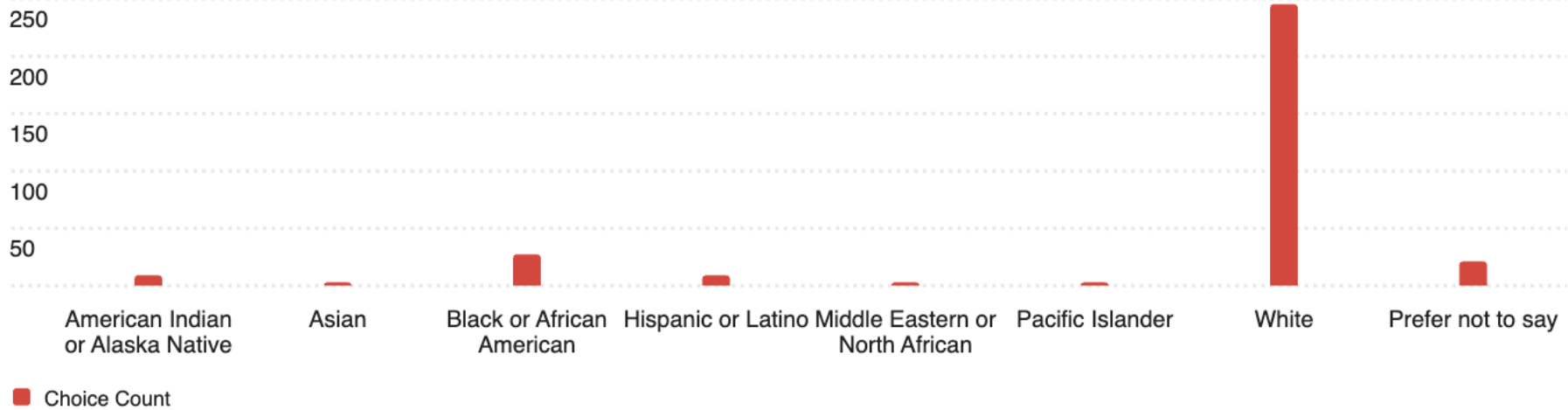
Q5 - How old are you (person living with a brain injury) now?



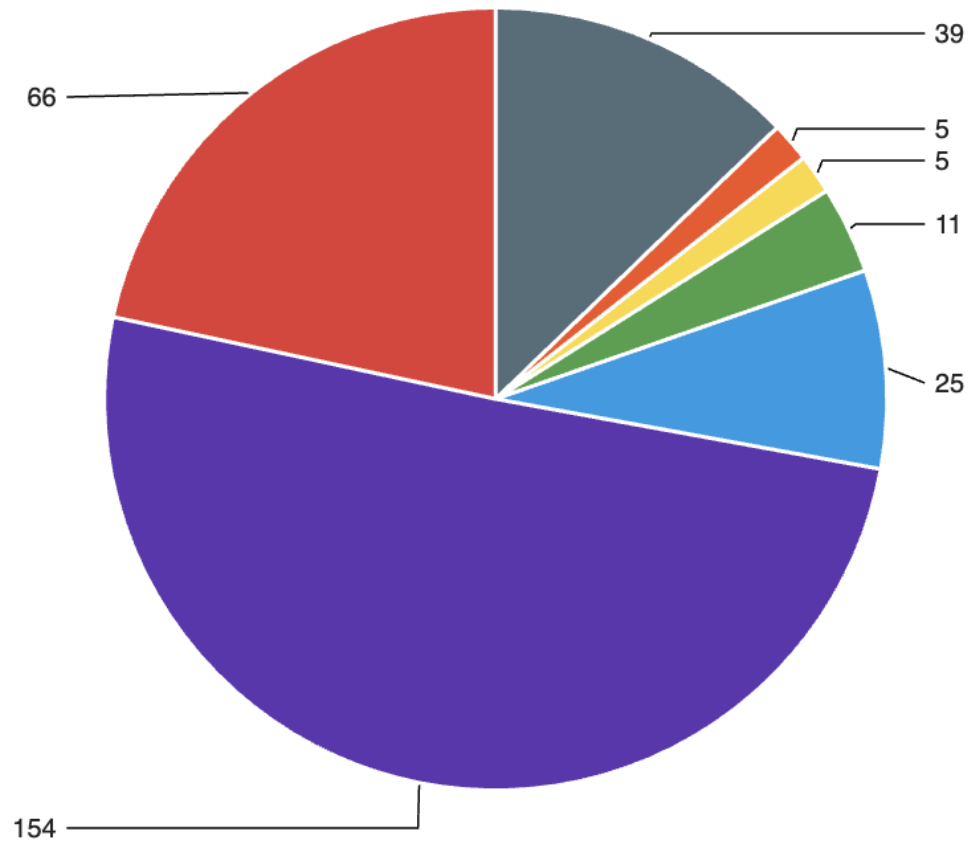
Q6 - How do you describe your gender? - Selected Choice



Q7 - How do you describe your race and/ or ethnicity? (Click all that apply.)

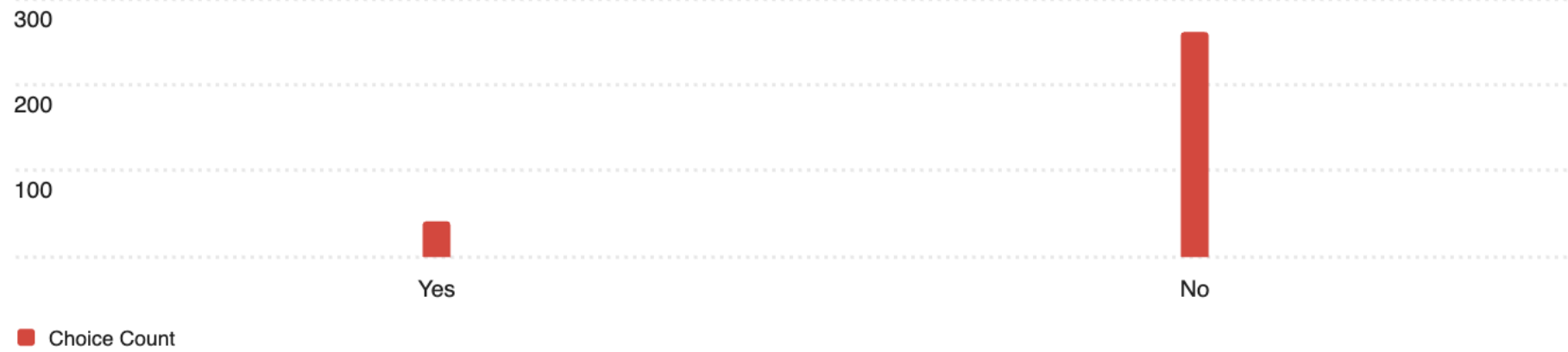


Q9 - Where do you (person living with a brain injury) live now? - Selected Choice

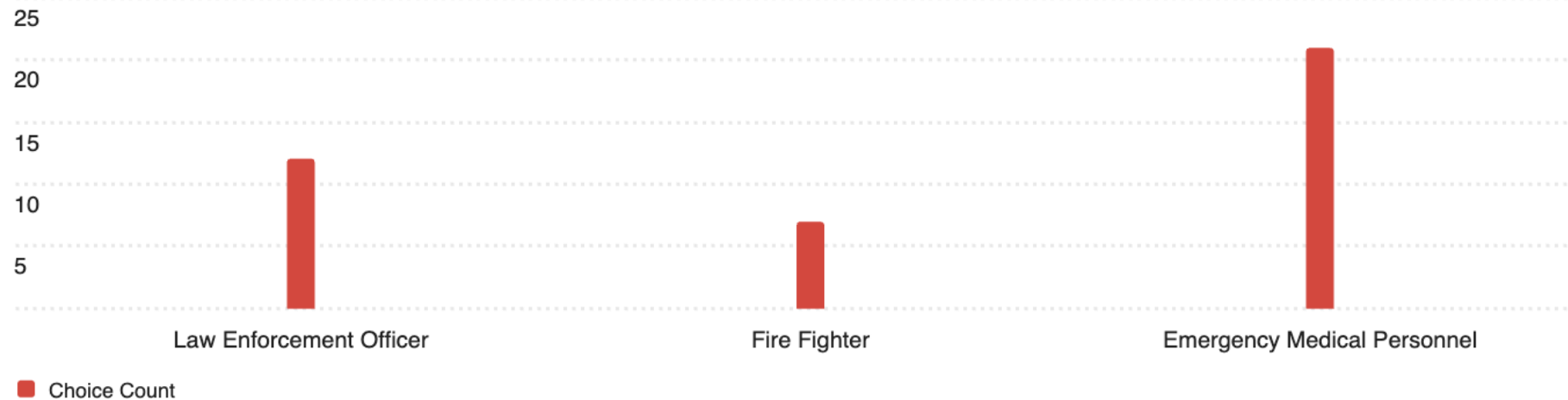


- Other, please describe
- Homeless
- Live in a nursing home
- Live in an adult-care home
- Live with roommate(s)/friend(s) in a home I/we own/rent
- Live with family
- Live alone in a home that I rent/own

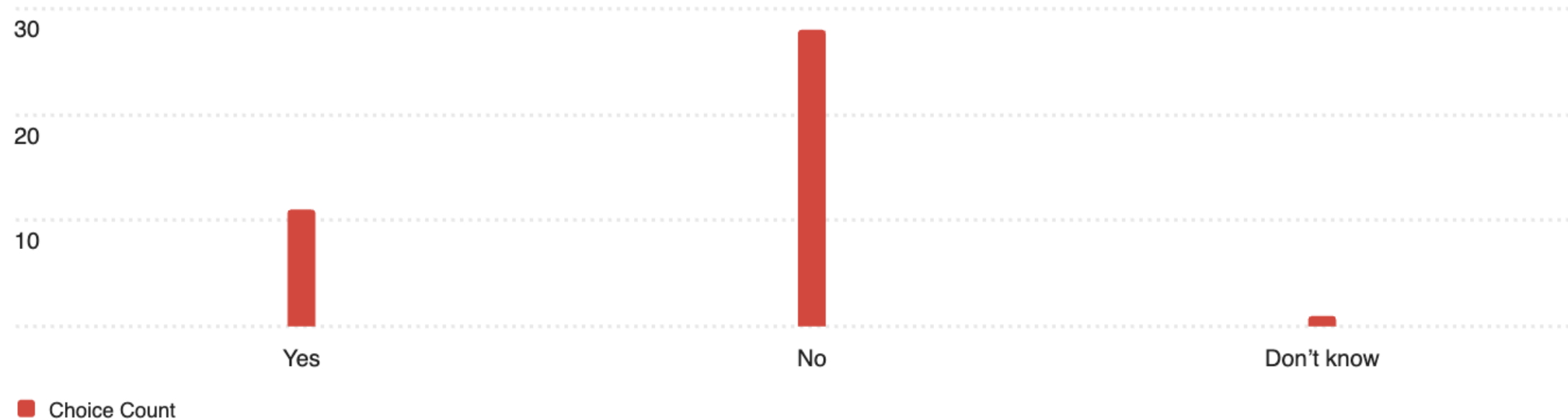
Q10a - Are you now or have you been a first responder (law enforcement officer, firefighter, emergency medical personnel)?



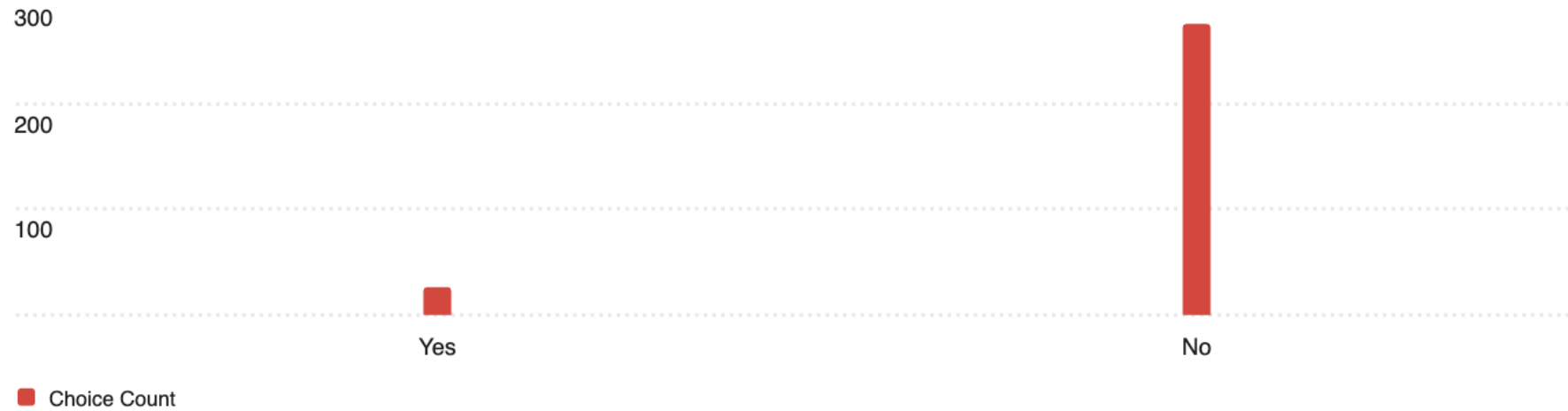
Q10b - If yes, what type of first responder?



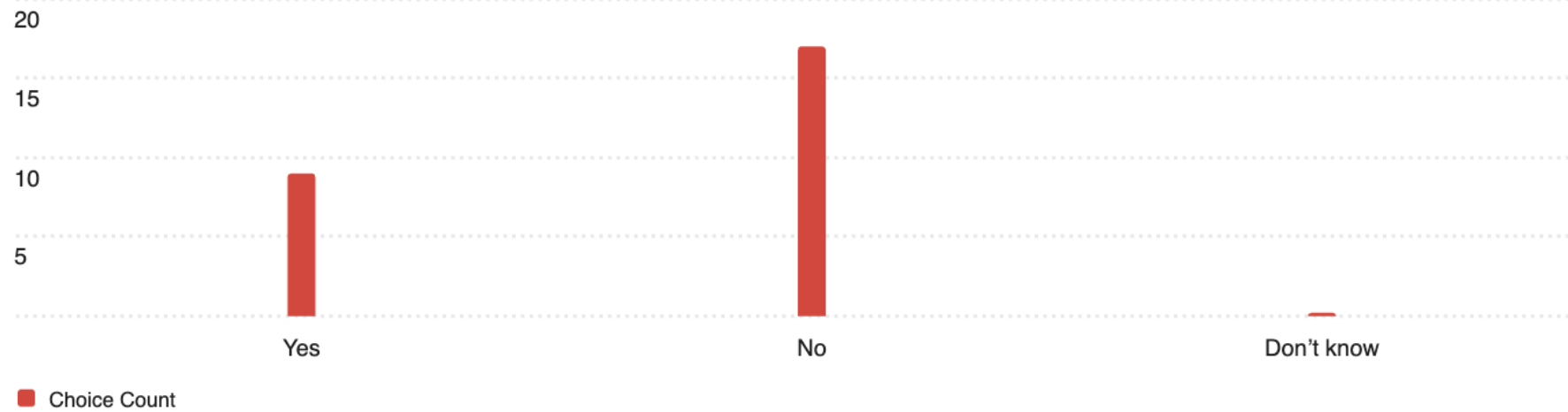
Q10c - If yes, was the brain injury sustained in the line of duty?



Q11a - Are you now serving in the military, or are you a veteran?



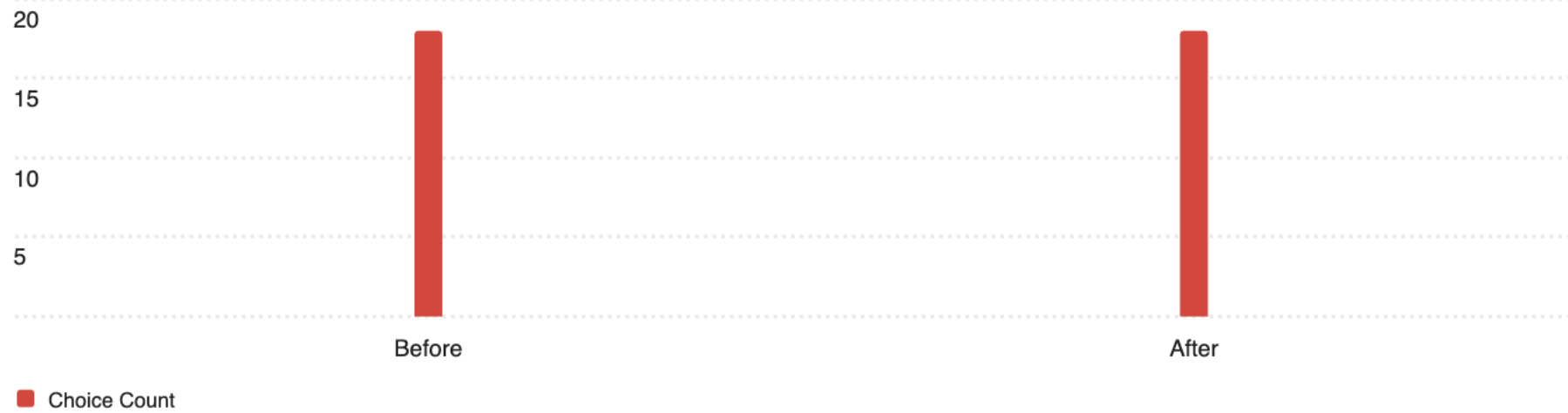
Q11b - If yes, was the brain injury sustained in the line of duty?



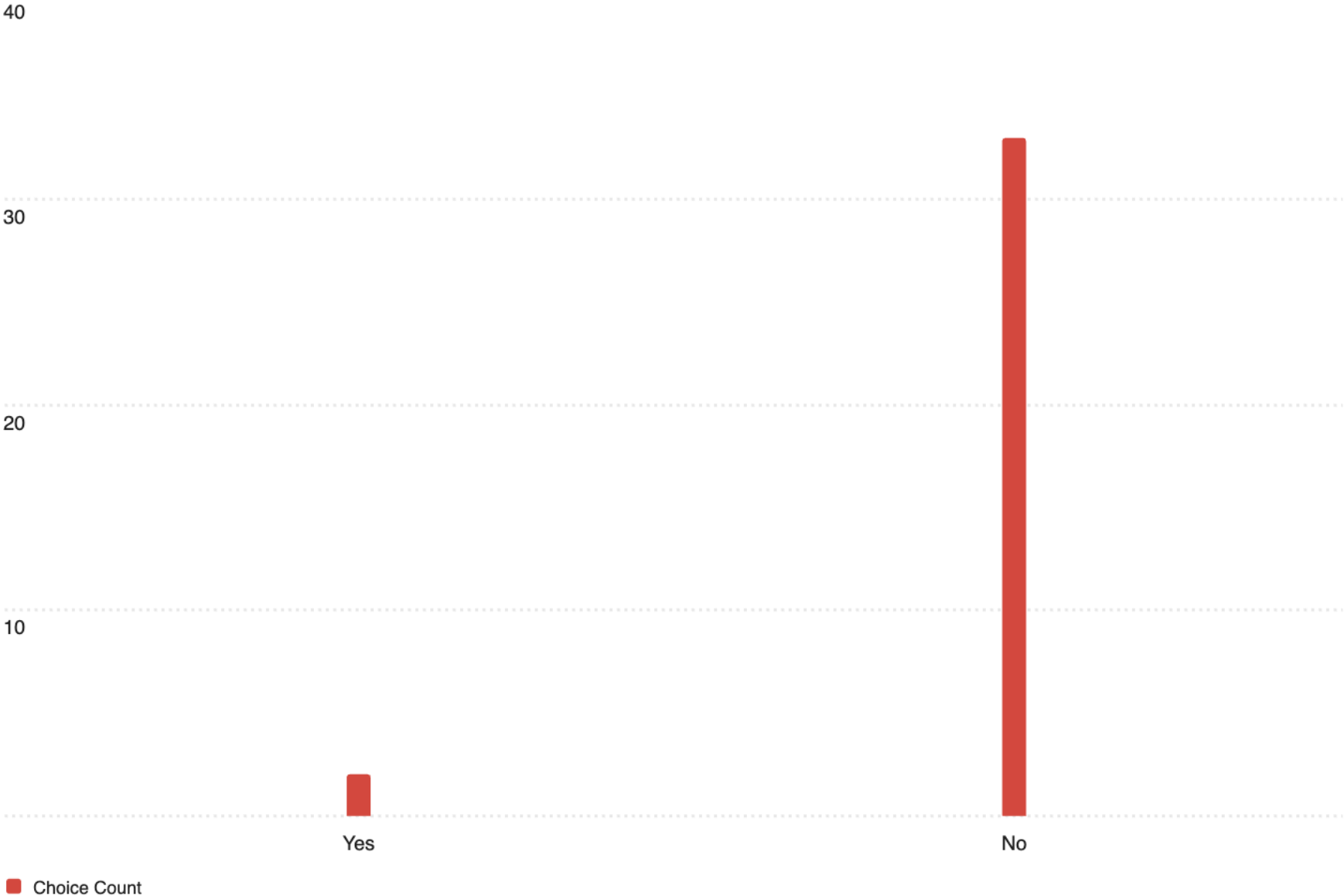
Q12a - Have you ever been incarcerated?



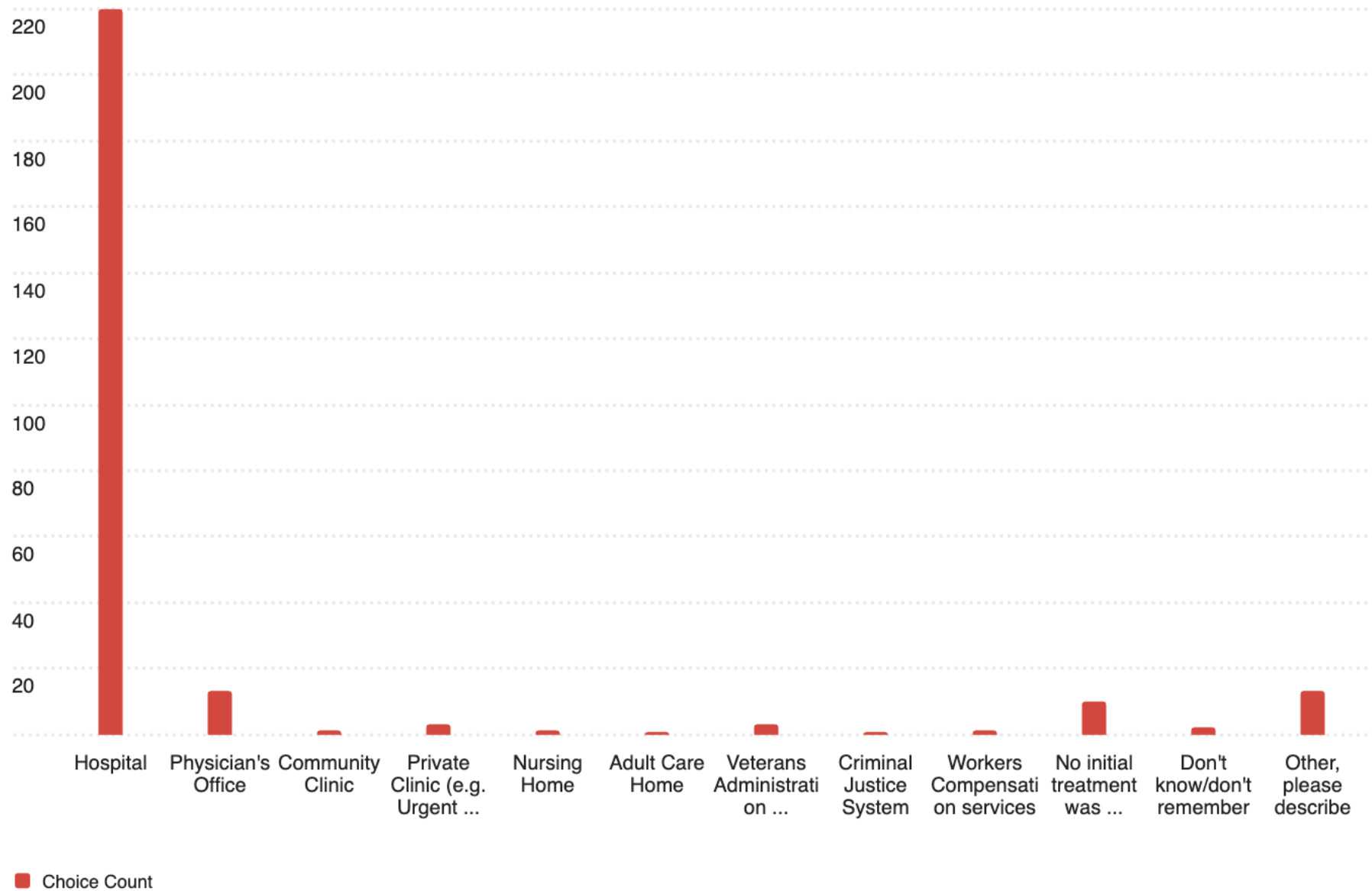
Q12b - If yes, was the incarceration before or after your brain injury?



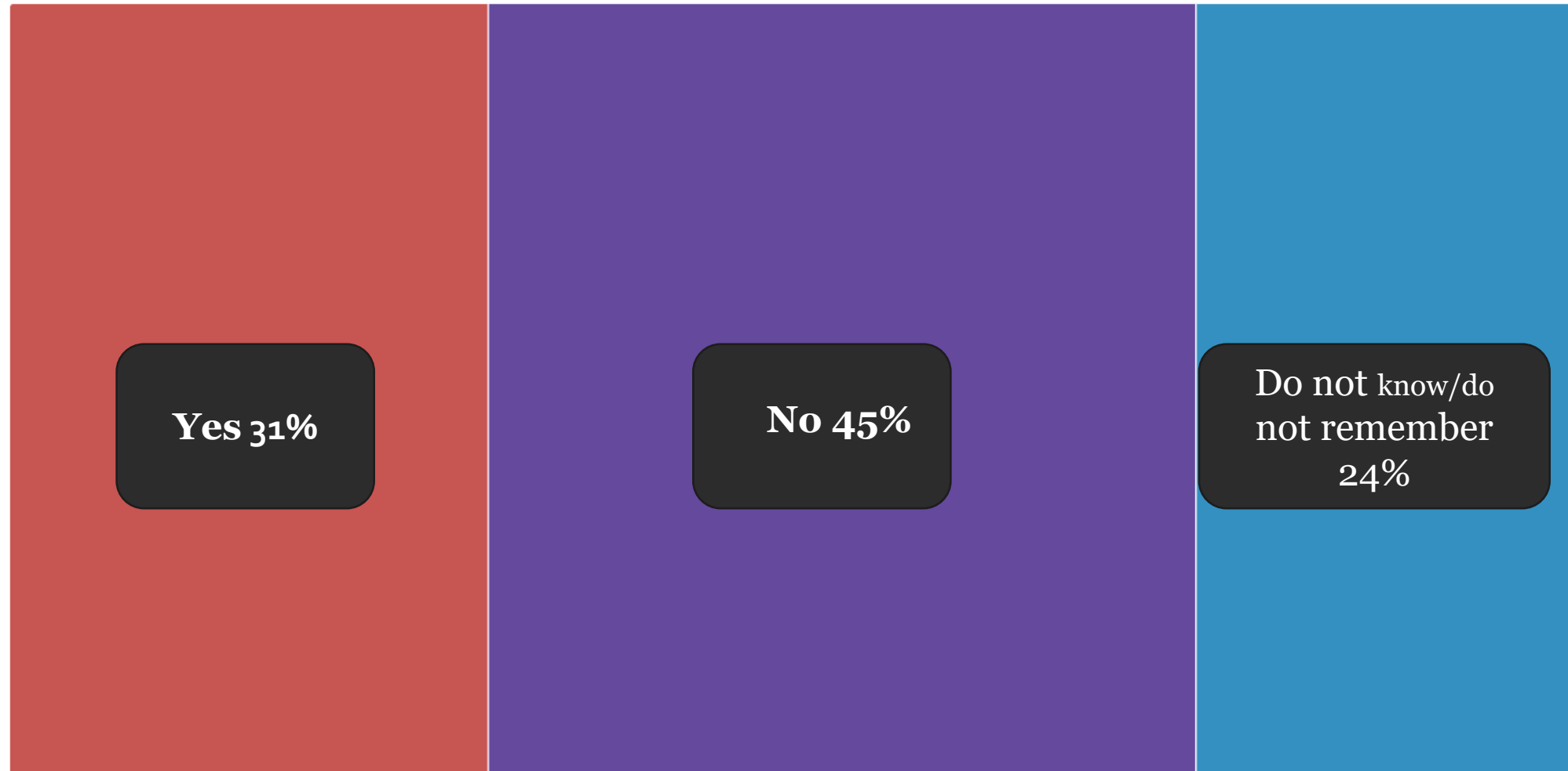
Q12c - If yes, did you sustain your brain injury while in a prison setting?



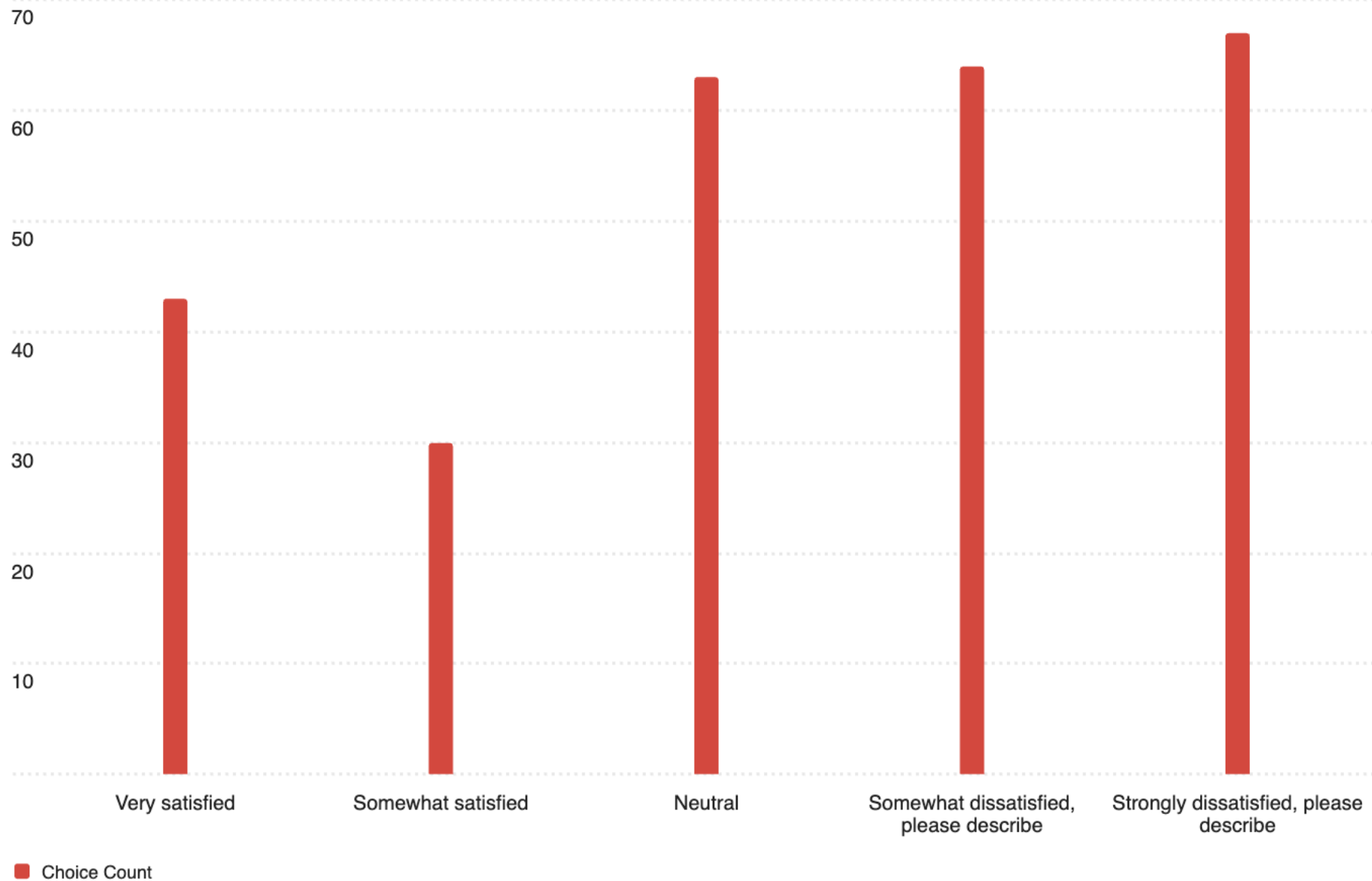
Q13 - Where did you (person living with a brain injury) receive initial treatment for brain injury? - Selected Choice



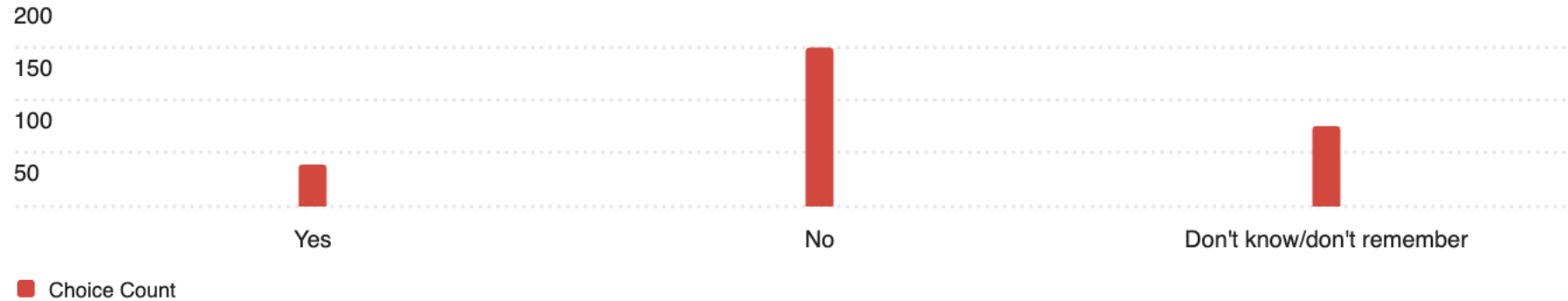
Q14 - Did your initial treatment provider identify, in writing, services and community-based resources specific to brain injury at discharge/before you left the physician's office?



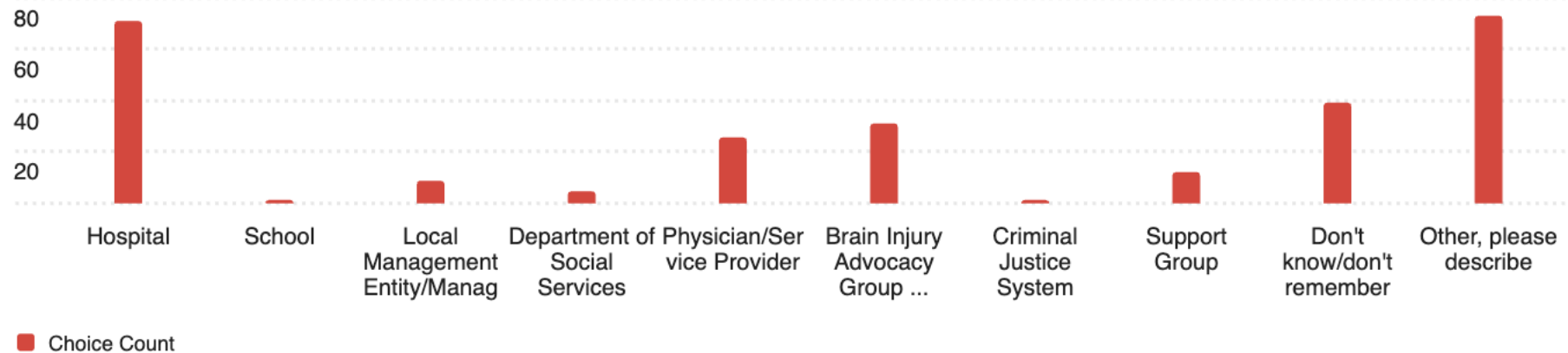
Q15 - How satisfied were you with the guidance you received about brain injury services and community resources before leaving the provider's office? - Selected Choice



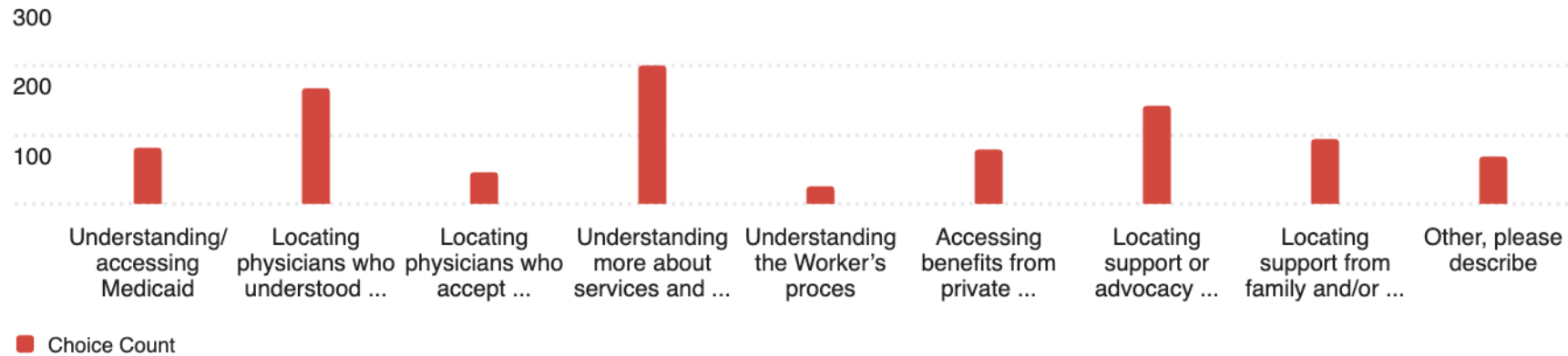
Q16 - Before you left, did your provider/doctor give you a contact name or phone number for your Medicaid program (Local Management Entity/Managed Care Organization/Tailored Plan) (LME/MCO/TP)?



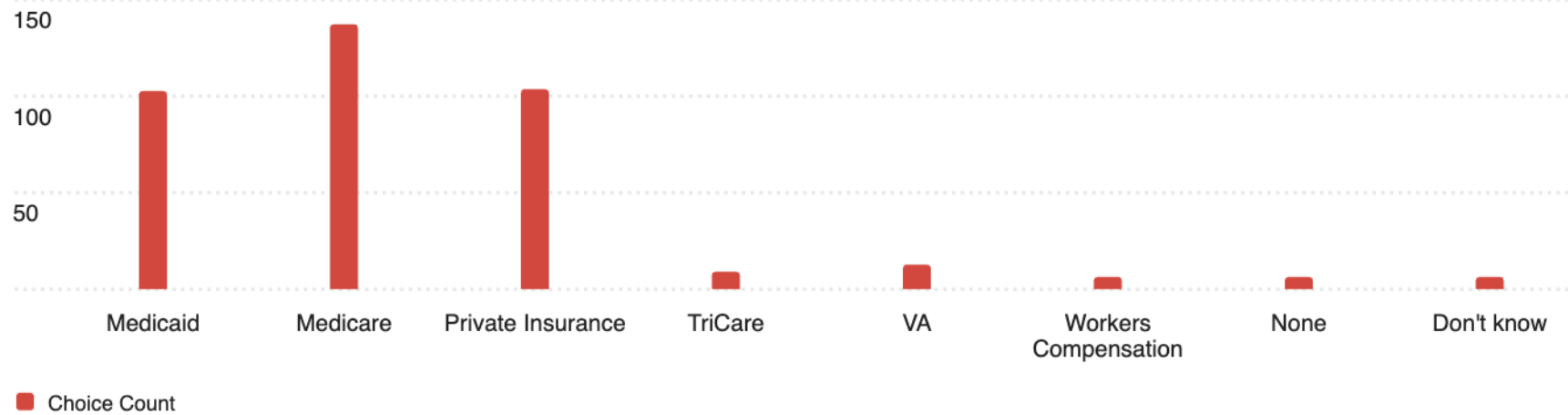
Q17 - Which agency provided your first guidance on how to access services specific to brain injury? - Selected Choice



Q18 - As a person living with a brain injury, what kind of assistance did you need when you first learned of your brain injury? (Select all that apply.) - Selected Choice

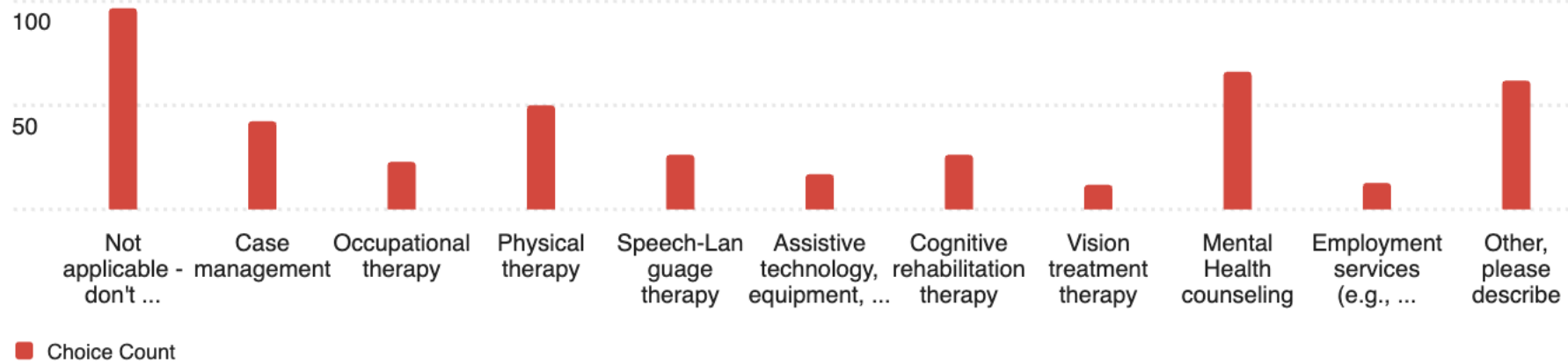


Q19 - What is your (person living with a brain injury) current insurance? (Select all that apply.)

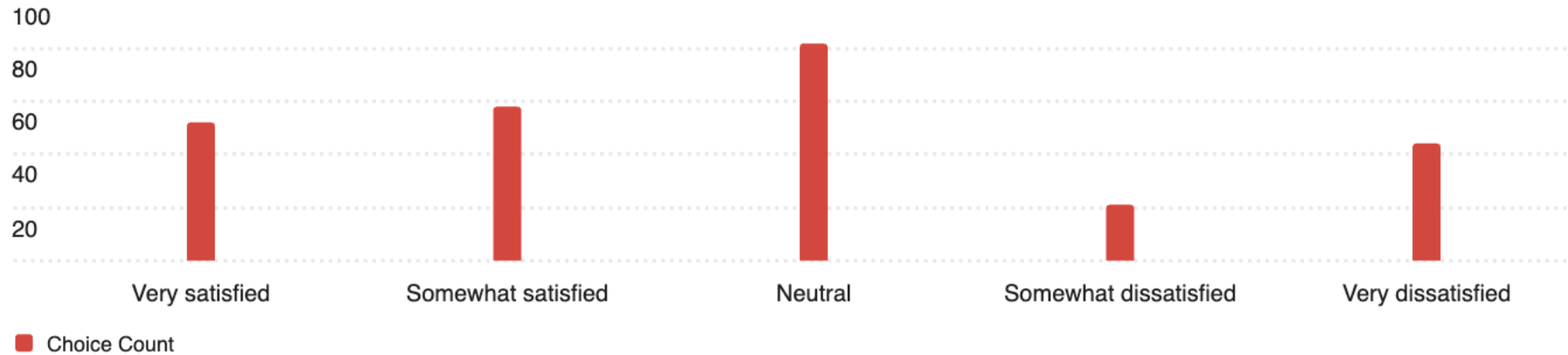


Q20 - Which brain injury-related services do you currently receive? (Select all that apply.) -

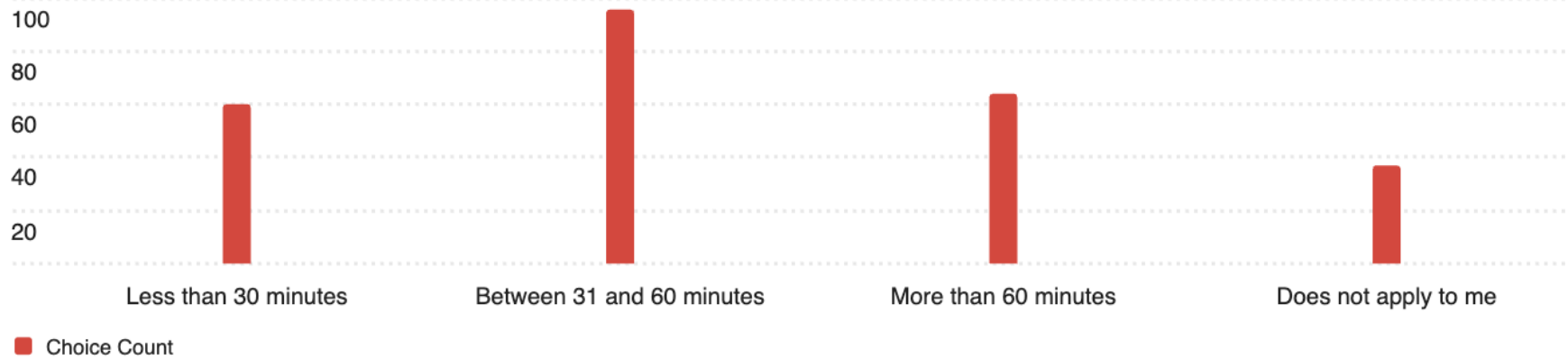
Selected Choice



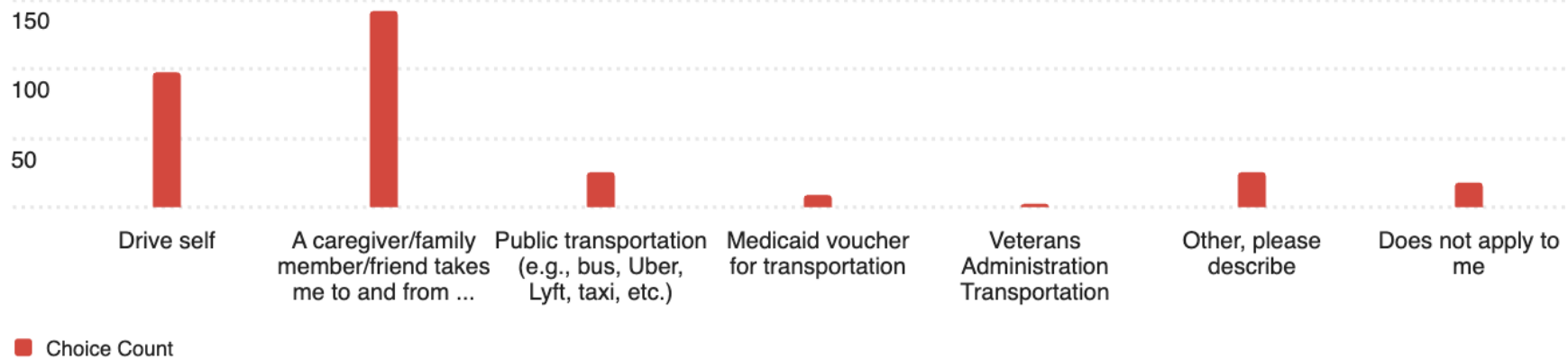
Q21 - In general, how satisfied are you with the brain injury-related services you are currently receiving?



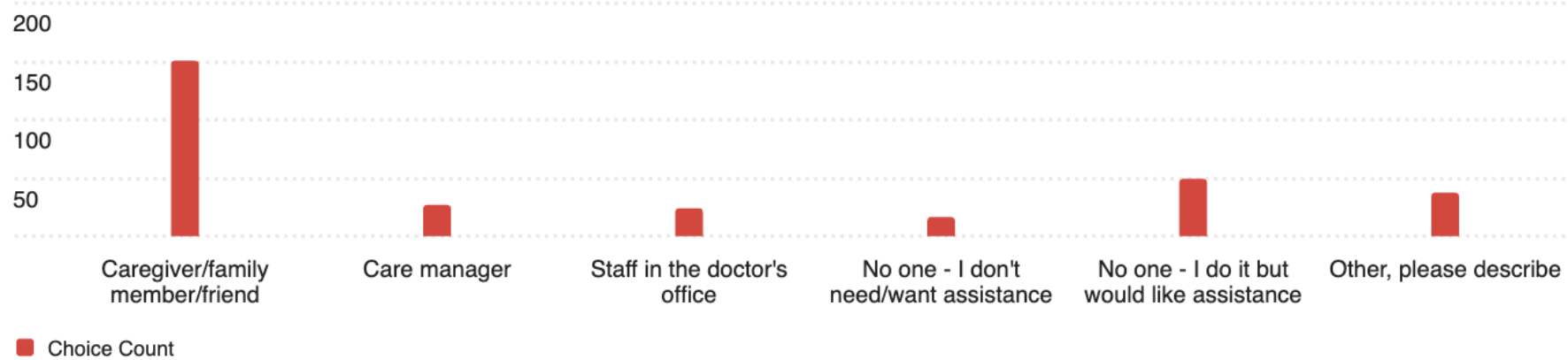
Q22 - What is the longest amount of time you currently travel ONE WAY to see a doctor or receive treatment for your brain injury?



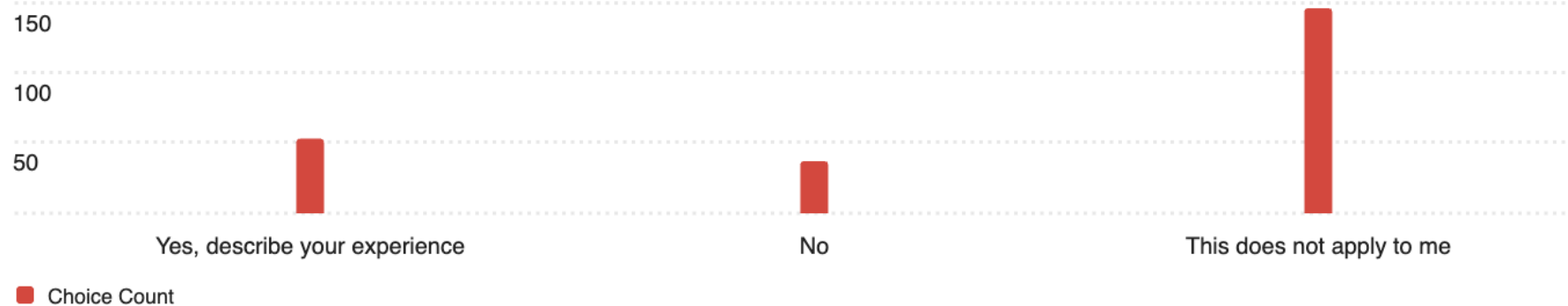
Q23 - How do you get to and from your appointments for services for your brain injury? (Select all that apply.) - Selected Choice



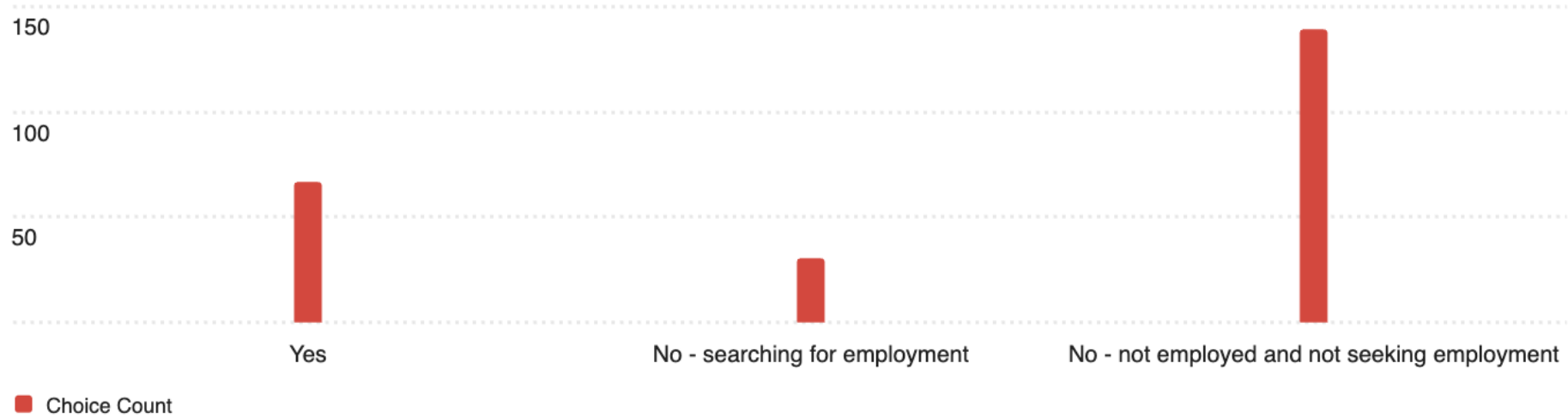
Q27 - Who assists you with "navigating the system" (e.g., getting services, figuring out insurance issues/needs, etc.)? (Select all that apply.) - Selected Choice



Q28 - When contacting your Local Management Entity/Managed Care Organization/Tailored Plan (LME/MCO/TP) for assistance, does a representative from the LME/MCO/TP return your call? - Selected Choice



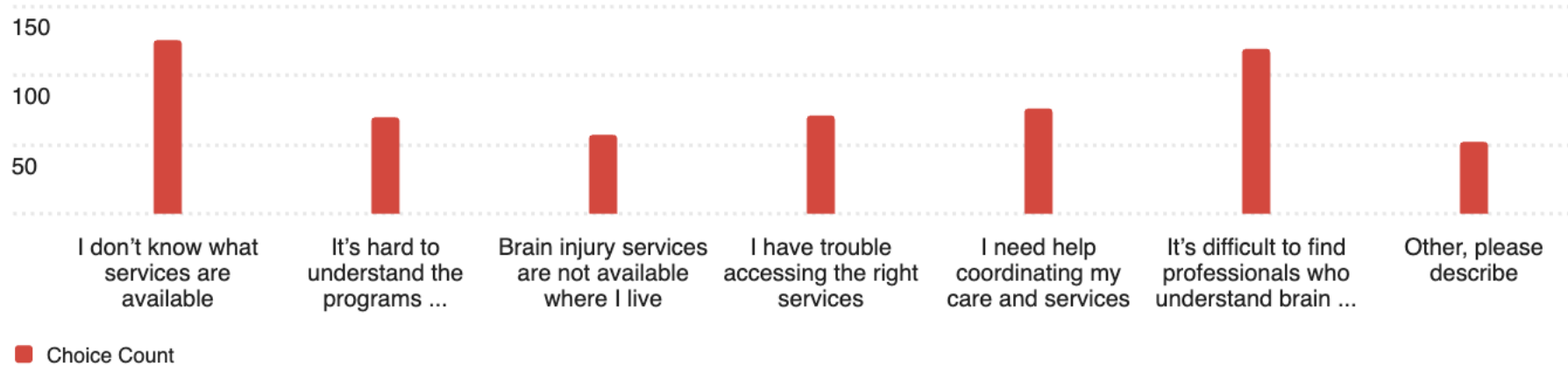
Q29 - Are you currently employed or seeking employment?



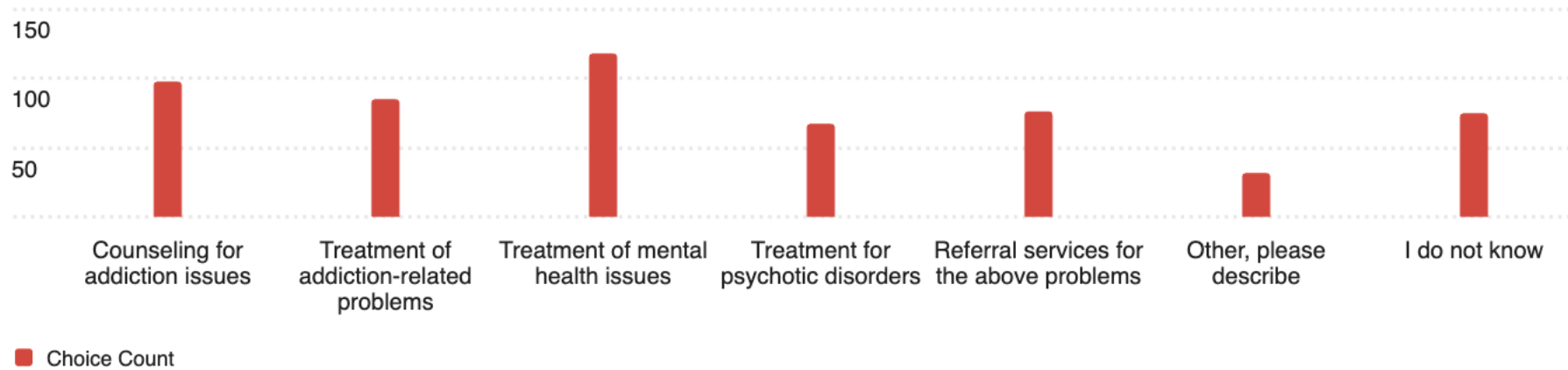
Q30 - If you are not currently employed, what is the reason? - Selected Choice



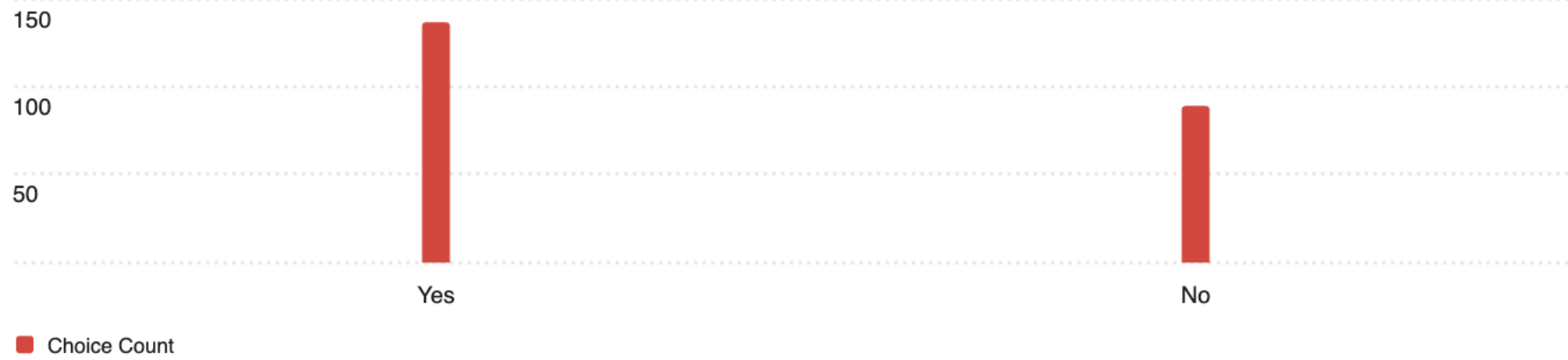
Q31 - What challenges do you face in getting support as someone with a brain injury (select all that apply) - Selected Choice



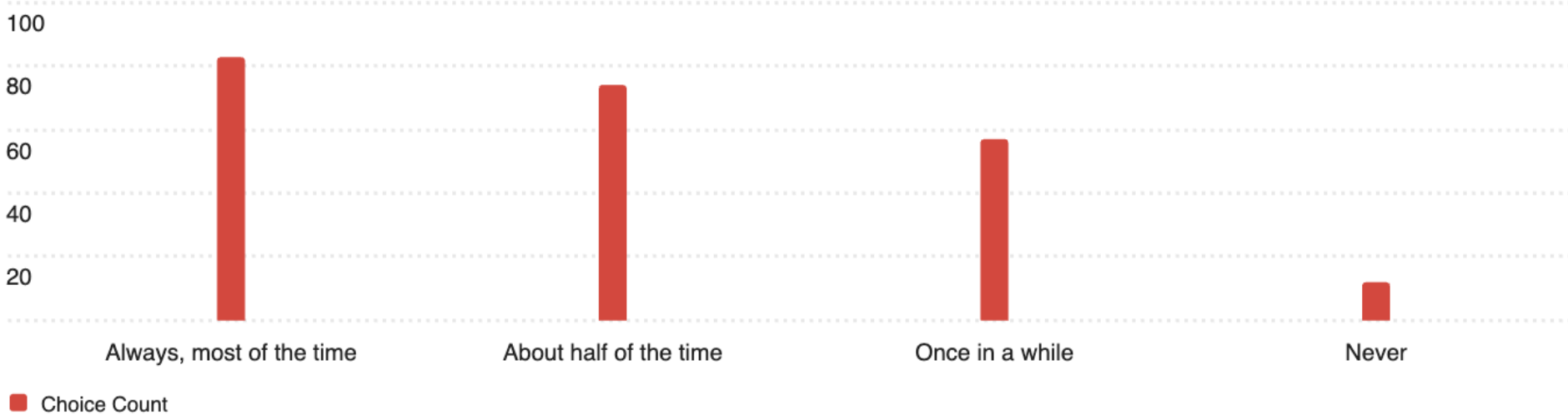
Q32 - Which routine services specific to mental health are available in your community? (Select all that apply.) - Selected Choice



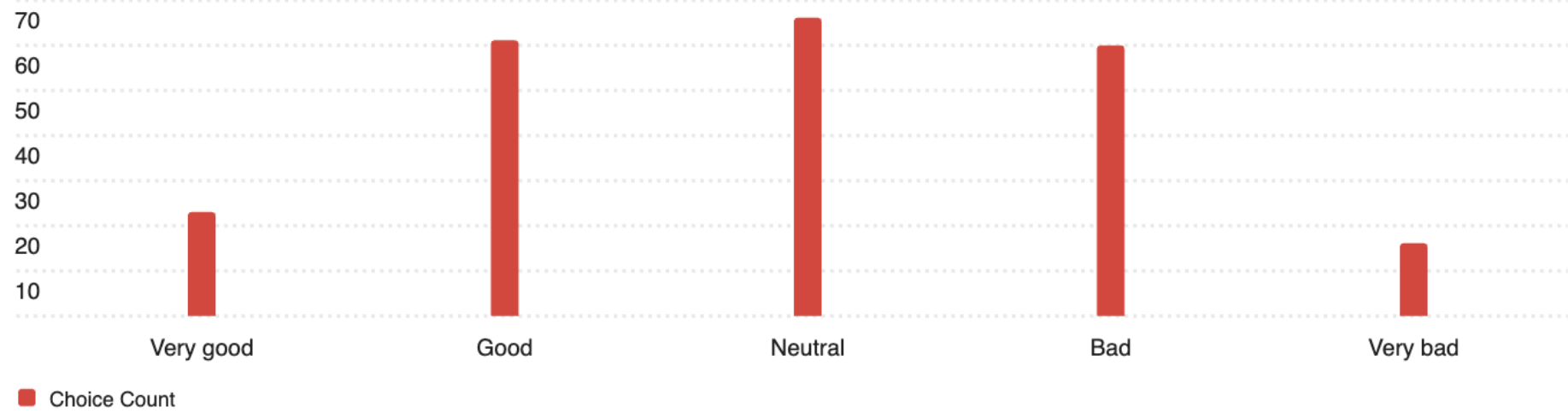
Q33 - During the past 4 weeks, have you had any problems with your work or daily life due to your physical health?



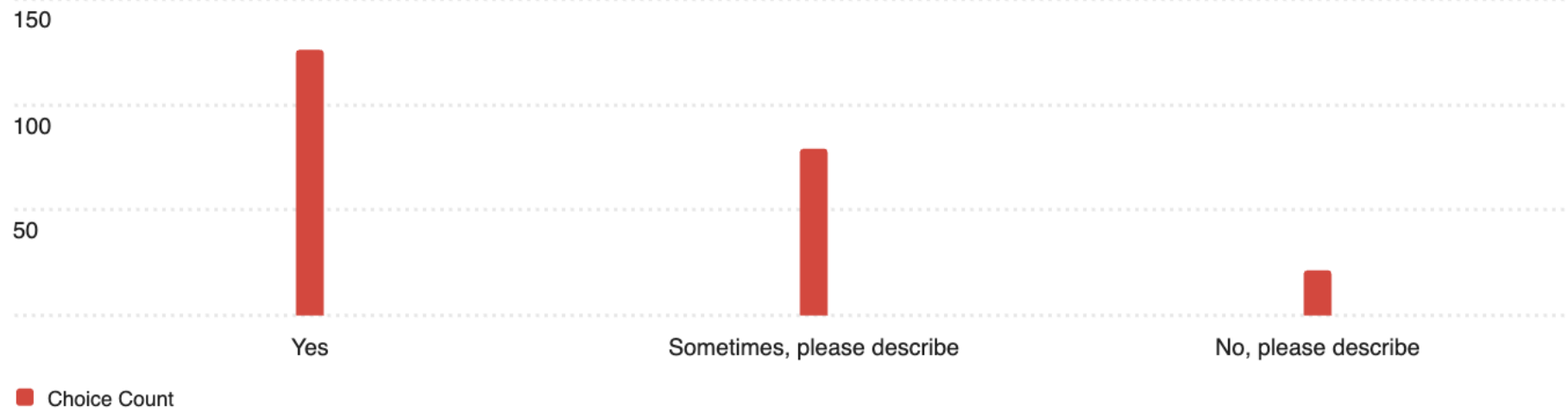
Q35 - How often do you feel positive about your life?



Q36 - How is your quality of sleep?



Q37 - Do you feel content with your relationships and family? - Selected Choice



Q38 - What treatment, need, or service is the most important to you right now?

What treatment, need, or service is the most important to you right now?

Talk to someone who understands my condition

I need a coach and accountability partner to make sure I achieve goals such as starting a business, email management, paper clutter in my office, etc.

Brain Wise Saves Lives wisdom as biking accidents happen every 21 seconds in the US as World.

Getting hospital grade bed and assistive devices

I don't know or understand how to manage most anything anymore

There are several but vestibular or eye movement therapy.

Physical therapy

Physical therapy is most important to me.

Exercise

Physical and Speech therapies

Helping 12yo navigate the world with a disability

Learning to walk again

Driving

Not sure

PT and adaptive activities and groups to socialize with.

I am receiving appropriate treatment and am satisfied with my current treatment.

support groups

? Disability

Serving as a TBI mentor

Other nonprofits that help with TBI

Q39 - What programs do you think would be helpful?

What programs do you think would be helpful?

This is too long, I was just in ER last night same answer as above

It would be helpful to have programs that pay for the co-pay for treatments, therapies, etc.

Brain Wise Saves Lives

Programs for loaner use or insurance help to families in dire need with financial issues

I don't know

I think expanding BIANC programs to the western part of the state would be beneficial and not leave so many of us feeling invisible or left out. I think that enhancement of medical technology and advocating for doctors/PA's/medical personnel to attend trainings to receive current TBI trainings and models.

Physical therapy and occupational therapy

I think having more physical therapy programs or occupational therapy programs would be beneficial.

Exercise

Programs for physical and speech therapy

Medicaid for all

Not sure....frustrating not being able to sing or write like I used to. I broke my back after stroke which forced me to end physical therapy.

Not sure

Programs for folks who are BIPOC (Black, Indigenous, People of Color - including Latino and Asians), non-English speaking, and for younger folks.

more support groups activities

? Ssi disability

No thoughts

More like yours

National Listing of quality not quack Cognitive Rehab Specialists.

Support groups and events closer that I can get to. Fun things that help the injured feel more "normal" and able. Financial help. Housing help. Educating the public and helping the injured feel more part of society and a gift to it.