

BEST PRACTICES FOR USING TBI REGISTRIES TO CONNECT PEOPLE TO SERVICES: A NATIONAL GUIDE

Prepared by the
National Association of State Head Injury Administrators
Maria Crowley, MA, CRC
Director, Professional Development

For the Administration for Community Living
TBI State Partnership Grant Workgroup on
Using Data to Connect People to Services

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ACL Data Workgroup

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Introduction

The U.S. Department of Health and Human Services Administration for Community Living (ACL) Traumatic Brain Injury (TBI) State Partnership Program awarded grants to states in 2018 in two categories: Mentors and Partners. These grantees were then assigned to workgroups established in accordance with topics relating to states' goals. The Mentor grantees who have expertise in each topic were to work with Partner states to help develop, implement and/or expand activities relating to these topics. Nebraska and Virginia were awarded Mentor Grants and lead the Workgroup on Using Data to Connect People to Services, working with Partner Grantees Alabama, Alaska, California, Georgia, Idaho, Kansas, Maine, Minnesota, Missouri, North Carolina Rhode Island, Utah, and Vermont. In addition, the workgroup opened an invitation to any state, both grantee and non-grantees, interested in this topic. Additional states in this work group include Indiana and Maryland.

Product development is one of the requirements by ACL for the workgroups. As a result, the Using Data workgroup determined state brain injury programs would benefit from a national guide related to how state governments can use data to connect individuals living with brain injury to services and best practices for creation, management, and reporting of collected data.

This guide includes:

- A history and purpose of TBI registries
- An overview of the systems using data to connect individuals with TBI to services
- Core elements and practices for development and support of a TBI data registry
- Common barriers that states face to obtain meaningful and accurate data
- An assessment of questions asked (data collected) by state registries across the US
- Other useful sources of data

Common Terms

Traumatic Brain Injury (TBI): Brain dysfunction caused by an outside force to the head. TBI can have wide-ranging physical and psychological effects. Some signs or symptoms may appear immediately after the traumatic event, while others may appear days or weeks later.¹

Data Dictionary: collection of names, definitions, and attributes about data elements being used or captured in a database. It may also describe the meanings and purposes of data elements within the context of a project, and provides guidance on interpretation, accepted meanings and representation.²

Incidence: the rate of occurrence of new cases of a disease or condition.³

Prevalence: the proportion of cases in the population at a given time rather than rate of occurrence of new cases.³

Registry: a collection of data about a particular group of people who share a common personal characteristic, for example development of the same disease.⁴

Surveillance: Ongoing systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated to the dissemination of these data to those who need to know and linked to prevention and control. The data collected typically includes demographic, socioeconomic and clinical characteristics of the population under surveillance, data on key outcomes such as disease complications and mortality, and data on potentially mitigating or aggravating behaviors or co-morbid conditions referred to as risk factors.⁵

Notes: The term state program is referenced throughout this guide. This term refers to the state agency designated as the lead agency for TBI via the state's governor or the entity that the lead agency designates to implement this work. State programs are the target audience of this guide.

As this document is supported by the ACL State Partnership Program, the term traumatic brain injury (TBI) is used throughout to refer to brain injury, even though some surveillance systems capture both TBI and other types of acquired brain injury such as strokes.

For the purposes of this guide, a TBI Registry is any mechanism used by a Lead State Agency (or representative) to collect data on individuals living with brain injury for the purpose of surveillance or to "connect people to services". This may include data collected from a state trauma registry, hospital association, or independently managed programs. We recognize that TBI registry efforts and methods vary state to state.

History and Purpose

Over the last forty years, states have been seeking accurate estimates of how many individuals sustain a TBI each year, and more importantly, what that means in terms of challenges, outcomes, and long-term recovery for state residents. In fact, a primary impetus behind creation and maintenance of a registry is to link individuals with challenges to services, and to establish statewide incidence to be able provide those services. For the purposes of this guide, a comprehensive literature review was conducted, but there is a dearth of current information related to the status, process, or impact of TBI registries.

Because TBI is the sudden onset of injury rather than a congenital or gradual change, incidence has historically been captured where and when people seek services for this new onset of injury, namely emergency departments and hospitals. As a result, states initially looked to trauma records located within hospitals, to create registries by accessing data from emergency departments and trauma centers admissions discharge data. However, not all injuries are captured this way, as many individuals do not seek medical attention right away or at all, due to economic or personal circumstances, or symptoms that are not readily linked to the injury (mild TBI, sports related concussions, intimate partner violence). Consequently, there are whole segments of state populations affected by TBI who are not captured by trauma data.

A general registry definition is included above. However, there is wide variation in the type and nature of registries, which can range from a simple list of people affected to a complex system of identifying, contacting, and providing case coordination to help people with the condition get the services they need.”⁵ This document is intended to provide an idea of the scope and nature of TBI registries across states and provide tools to equip states to secure the most comprehensive surveillance and linkage system as possible.

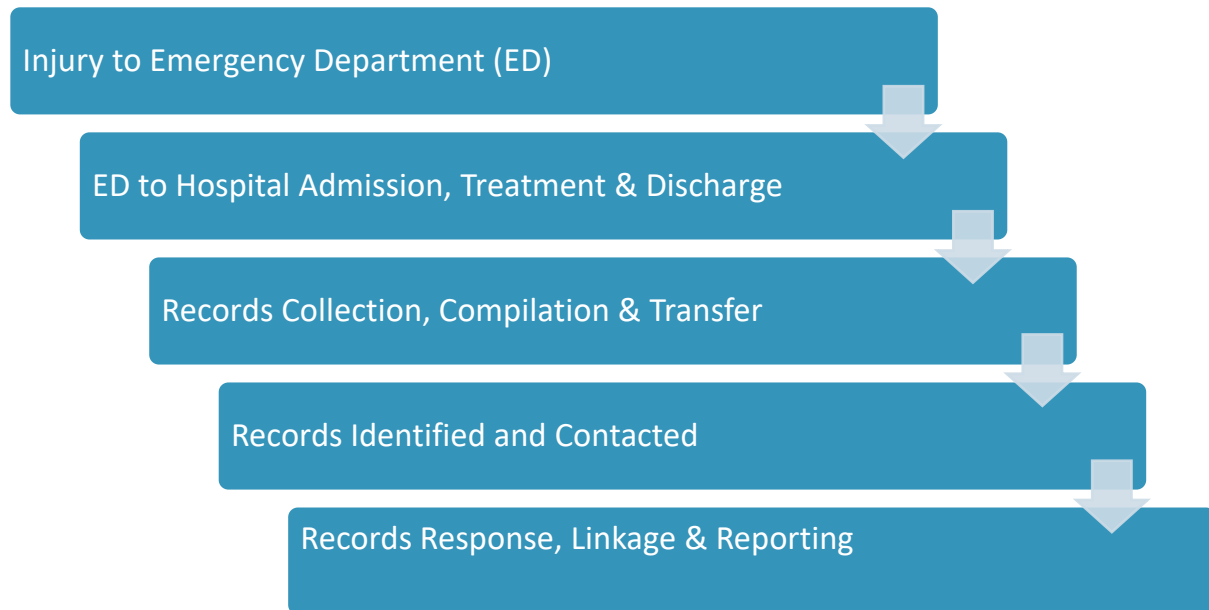
CDC further addressed the following areas regarding registry function and funding: data collection; identification; linkage to services; follow-up data collection (longer-term issues); and funding supports.

For many states, the purpose of a TBI registry is generally defined as a mechanism to:

- Identify how many residents in a state sustain a TBI each year.
- Know the number of individuals living with TBI and dealing with the challenges that accompany TBI.
- Connect these individuals and those who support them to the services they need to be successful in home, community, school, and work.

Registry Process

Typically for a significant TBI, the process looks similar across state Emergency Management Systems (EMS) and hospitals. States solely focused on surveillance implement steps 1-3, and states using registries to connect individuals to services implement steps 1-5:



When individuals sustain a TBI through causes such as a motor vehicle crash, a fall, or other blunt or penetrating blow to the head, they are taken to the hospital. If the injury is deemed serious enough to require emergency department and hospital admission, individuals are treated and the length of stay depends on several factors (level of severity, injury to other body systems, overall health, insurance, age, etc.). Once treated, individuals are discharged to a variety of settings: home, post-acute care, nursing homes, corrections, or other facilities. Hospital staff record trauma, diagnosis, demographic and treatment information, compile and securely transfer records to a data system managed by an entity allowed to receive it. This transfer usually involves state health departments, who in turn review and analyze data for surveillance and reporting purposes.

Beyond that, for states with agreements in place and the ability to receive and manage records, TBI data might then be transferred securely once more, or managed in-house, for contact and response regarding need. A letter and possibly other resource materials are mailed to eligible individuals, stating the purpose of the registry, and providing contact information in the event the individual would like to access information, resources or supports. The individual can then choose to respond, access, and receive services and supports, which vary state to state. The responsible entity collects information about the contact and response, as well as referral results, demographics, and injury specifics, and reports are disseminated to the state

department, advisory board and/or state legislature. States use this information to determine the amount and type of resources to provide, as well as mechanisms for support and service delivery.

The importance of linkage cannot be overstated. Depending on the complexity of their injuries, individuals and families are often overwhelmed by cognitive, physical, and emotional challenges that accompany a moderate or severe TBI. Once discharged, the ability to contact individuals with TBI is critical to connecting them to the services and supports that they and their families need to be successful at home, community, school, and work. Ideally, information about supports should be conveyed to survivors and caregivers at all points along the process, from hospital admission throughout treatment and discharge, and when home, but these connections are not always made. Funding plays a part in the ability to provide resources at all these points but is not the only barrier. Often individuals return home and do not know where to look or even what they need in order access services. Even if they receive information at the hospital about post-acute and community-based services, they might not access services immediately or at all. The individual may lose or be unable to retain the information provided, or they may believe that they will not need to access services as life and function will return to pre-injury management. An individual's support system might also have difficulties navigating services, and many times an individual has no support system at all. All the while, individuals with TBI may have an increased need for community-based services.

Reporting can occur for surveillance and for linkage and may be handled through the same or through different departments depending on who is collecting the data, who is providing the linkage, and what the state law mandates. Reporting might include information on incidence, injury, funding, information and referral and service delivery. There is great variety across state systems as to information collected and reported, the frequency and type of reporting, and additional activities based on the data. States can utilize results to generate funding and program requests, or impact legislation related to TBI broadly (helmet use, motor vehicle/driving laws, insurance, etc.).

Barriers to Success

While seemingly straightforward, the process from injury to service delivery intervention can involve numerous steps that can interfere with identification and connection to services. States participating in the workgroup reported on several barriers to effective surveillance and linkage:

- Registries can be an unfunded mandate. Even though staff work hard and invest time and energy, no one is dedicated fully towards operation, quality control, analysis, or reporting. A lack of financial support might cause difficulties in gaining traction or

securing agreements. Funding helps to ensure efficiency, accuracy, and analysis for future steps. State cuts make it even more challenging to have comprehensive data and linkage procedures in place.

- Although records are collected and compiled, they can be incomplete. Contact information might be inaccurate or missing. There is also no mechanism for gathering mild TBI records or data other than ED records. Physicians are not required to report TBI injuries treated in offices or clinics, nor is there a mechanism in place to capture non-hospital care. Individuals within underserved populations (such as those who are homeless, incarcerated, ethnically diverse) who are treated by hospitals are likely to be under-reported. Many do not seek treatment.
- Records can also be incomplete due to inaccurate/missing coding, or coding changes, which might screen in or screen out those needing contact. Smaller hospitals that do not often treat individuals with TBI might utilize different coding than larger hospitals.
- Many systems only allow for one contact per person per event. Individuals have the best chance for success if contacted multiple times along the recovery process. Individuals who live out of state, although injured in the state where the surveillance occurs, might be ineligible for contact. There are no official regional registry agreements in place to allow for contact.
- Data might be incomplete due to non-compliance of submission or existing regulations only allowing submission from certain hospitals (level 1 trauma centers only, for example). Many statutes are lacking consequences for non-compliance. If records are transferred from one agency to another for linkage purposes, states are dependent on the responsiveness of the data management agency.
- Inadequate or older data systems at hospitals or state agencies can cause challenges with timeliness and accuracy of contact as well as reporting.
- Response rates for linkage are low, impacting awareness and receipt of services and supports. Even though individuals and families might receive contact information in the mail, they might not read it, feel that they do not need it, or might be hesitant to respond. There might also be reading, language or cultural barriers impeding the receipt and processing of the letters. If individuals do not return to home, they might not be eligible for services (those in nursing homes, prison, etc.).

Registry Development and Implementation

With all the hurdles state surveillance/linkage systems can present, states are still supportive of maintaining their efforts. Registry data gives states an indication of incidence of TBI, and more importantly, a mechanism for connecting individuals to the services they need. For states who are trying to establish a registry, there are several points to consider, and several factors must be in place. These questions can be useful in determining how to proceed with registry planning and implementation:

Purpose

1. Why does your state need a registry?
2. Would your registry capture incidence for surveillance purposes only, or to plan and execute service linkage?

Data Sources and Protocols for Collection

1. What data sources are available in your state? Trauma, hospital admissions or discharge?
2. Are there other data sources that could be useful as well, at least in terms of surveillance? (Later in this document, additional data sources are presented).
3. If you are developing a formal registry system, then legislation might be necessary for required data collection. Will you need new legislation, or can you modify existing legislation to pursue collection? It might be possible to link a TBI registry with an existing data/trauma collection process (such as strokes or burns).
4. Who can help to support pursuit? Are there other organizations that need to be involved, such as the state department of health? Are there organizations that might be wary of data collection elements or results?
5. Is there a state agency designated to obtain and maintain data? Does that agency have the necessary infrastructure in place to support a system? Will a different agency be responsible for linkage?
6. What kinds of requirements would be necessary for collecting data, and what gets submitted? When? How often? Where will it be stored? How will it be managed? How will confidentiality be ensured? Who can have access to it and to what end? Is there a consequence for not submitting data?
7. Is there someone who can accurately analyze and interpret collective data findings? Is there a process and timeline in place to determining and conducting strong data analysis?

Linking Individuals to Services

1. How will individual records be contacted for linkage? When will contact occur and how often? Who is ineligible for contact? What are the best mechanisms to follow for contact? What procedures ensure the most response? How can confidentiality be maintained?

2. Once contact is made, what information is collected? What are the supports in place that will be provided? How will individuals be linked to those services?
3. Are all the agencies or organizations collecting or benefiting from TBI-related data willing to collaborate?⁶

Once a state can answer the questions above, these steps will be useful for establishing a process for implementing and maintaining a registry. Many states coordinate efforts with the TBI Advisory Board or Trust Fund Council as well as across department and systems:

1. Talk with other states about their registry process, data elements, collection, legislation, linkage and reporting, and lessons learned while implementing.
2. Ensure there is authority in place to implement the registry and to require healthcare providers to report. Certain elements such as the state agency responsible, agency uses for data, and mechanisms for service linkage to connect with resources will be conducted.
3. Ensure a protocol for assuring confidentiality through agreements or other formal processes. A sample is provided within *additional resources*.
4. Identify the entity to receive the data and how it will be used, such as the state department of health.
5. Determine what data elements will be collected, as well as a mechanism for collection and review and disseminate to data sources and agencies responsible for managing data.
6. Develop a process to collect and analyze data, as well as a process for linkage and reporting.
7. Develop a budget that covers all aspects of protocol, process and analysis as well as staffing, data storage, contact and outreach materials and data manipulation.
8. Consider a pilot project and then review findings before launching a statewide collection and linkage system.
9. Determine who will be responsible for responding to contacts and the level and type of information that will be shared, as well as how contact and referral will be documented, such as the state's lead agency for TBI.
10. Obtain and develop information on resources and assistance to provide to respondents when contacted, and materials needed and available for mailing or online access. Materials and resources should cover the recovery trajectory from home services, education, rehabilitation and beyond to community service provision.
11. Ensure that supports are in place, informed and prepared to receive and to document referrals in community, school, healthcare, or vocational services.
12. Determine how data will be analyzed for improving the system as well as for securing additional TBI-related funding and other mandates.

13. Disseminate registry reporting and results to establish incidence, cause, risk, vulnerable populations, and work towards increasing TBI awareness, prevention measures and improving state supports.

Other Considerations

In addition to how each state system collects and reviews its own data, there are other considerations for how to best implement and maintain a registry.

State Hospital Associations are a key player as they represent and serve all types of hospitals, health care networks, and their patients and communities. The role of hospital associations cannot be underestimated, and they can provide strong support for moving forward if informed. As protectors of the best interests of healthcare institutions there might be some concerns about how a registry could negatively impact patients, billing, insurance, or legal matters. One hospital might be compared to another one, which could have adverse effects as well. Certainly, a punitive or legal consequence of non-compliance for data collection or submission might not be viewed favorably. For these reasons, consider discussions with the state hospital association if seeking registry legislation so that passage goes smoothly.

Data elements are also especially important in terms of information collected. Carefully consider all the data elements that will help to provide the most comprehensive information and will be useful in terms of creating reporting to guide future enhancements in linkage or funding. Most states utilize a data dictionary, which outlines and describes the meaning and purpose of the data elements, and provides rules for usage, application guidance on interpretation, and accepted procedures related to them. A data dictionary sample is included within the *additional resources* section. For best results, providing initial and ongoing training on data elements and records submission to hospital staff responsible for compiling records is critical. Staff need this training, as data elements might be updated, or staff turnover occurs within hospitals. States might also find it useful to share with hospitals what happens after they submit records, what is the “rest of the story” in terms of connecting individual to services. Communication might serve as a reminder of the importance of collecting complete and accurate records.

There are several factors to consider in terms of **data analysis** that can impact reporting. Several states optimize data collection with extensive analysis through a department or independent epidemiologist, someone skilled in observing patterns of frequency, cause, and effect, and recommending strategies for improvement in healthcare outcomes. This depth of analysis might be beneficial for indicating areas of need for additional funding or changes in legislation.

Additional Sources of Data

Although a traditional system of surveillance and linkage has been obtained and maintained by several states, there are other sources of data that could potentially enhance a state system related to TBI incidence, prevalence, and linkage. Due to the nature of TBI, individuals can exist within any other system at any other time with a diagnosed or undiagnosed injury, receiving services that might or might not be optimal for them. It is important to know about other sources in place that states ultimately could connect with to maximize analysis and reporting. This could lead to stronger infrastructure development and enhancement of services. Here are just a few:

Established in 1984, the **Behavioral Risk Factor Surveillance System (BRFSS)** is a national system of health-related telephone surveys collecting state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. BRFSS now collects data in all 50 states, the District of Columbia and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world. CDC continues to work with state and territorial partners to ensure that the BRFSS continues to provide data useful for public health research and practice and for state and local health policy decisions.⁷

Developed in 1990, the **Youth Risk Behavior Surveillance System (YRBSS)** monitors health behaviors that contribute markedly to the leading causes of death, disability, and social problems among youth and adults in the United States. Six categories of health-related behaviors are included: behavior contributing to unintentional injuries and violence; sexual behavior related to unintended pregnancy and sexually transmitted diseases; alcohol and drug use; tobacco use; dietary behavior; and physical activity. YRBSS is a system of surveys conducted by the CDC and state, territorial, tribal, and local education and health agencies.⁸

The **VA Traumatic Brain Injury (TBI) Veterans Health Registry** contains information about Veterans who served in Operation Enduring Freedom (OEF), Operation Iraqi Freedom (OIF), or Operation New Dawn (OND); showed symptoms associated with TBI; and sought care or benefits from VA. The construction of the registry and its maintenance is mandated by Congress. Veterans in the registry meet any one or a combination of these conditions:

- Screened positive on the VA health care administered screen when Veterans seek care.
 - Had a TBI related diagnostic code in their electronic medical record.
 - Applied for benefits for TBI as shown in the VA disability benefit file.⁹
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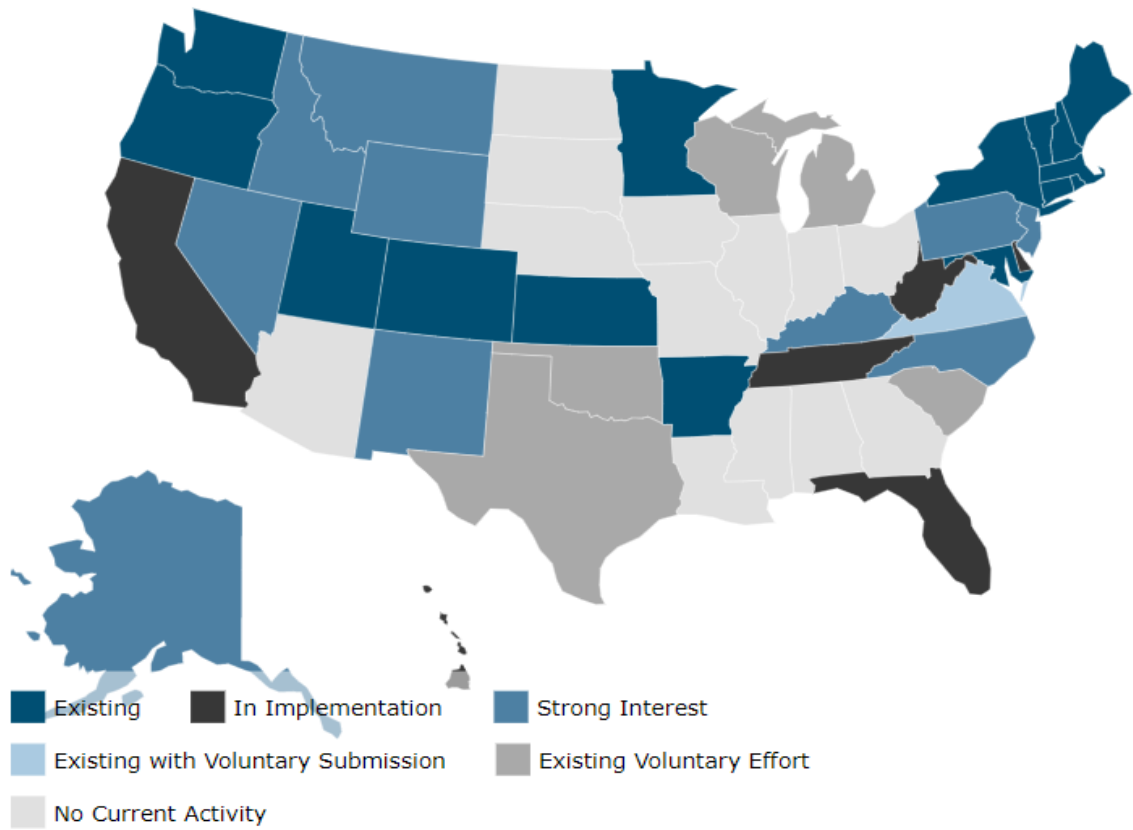
National Core Indicators (NCI) is used across states to assess the quality and outcomes of Developmental Disability (DD) and Aging and Disability (AD) services provided to individuals and their families. NCI offers valid, reliable, person-centered measures that states use to demonstrate how publicly funded supports (State Medicaid, aging, and disability agencies) are impacting people's lives and to determine where quality of those supports can be improved.

Over 46 states participate in NCI for DD and 22 states participate in NCI AD. Participating states use the data to measure and improved important elements of person-centered planning, services, outcomes, satisfaction, and policy.¹⁰

The CDC estimates that current data sources only capture one in nine concussions annually across the US. To capture a much more accurate picture of concussion, the **National Concussion Surveillance System (NCSS)**, enacted in 2018 but still unfunded, will accurately determine how many children and adults sustain a concussion each year and determine the cause. In addition, the results of a national system would inform and equip leaders within communities and states across the U.S. by:

- Creating national estimates of the number of people living with a TBI
 - Providing the first national estimates of sports-related concussions among youth that occur both in and outside of organized sports
 - Providing information about the most common causes of concussion injury, including motor vehicle crashes, falls, and self-harm
 - Monitoring trends to understand whether the number of concussions is increasing or decreasing, and assessing whether prevention efforts are working
 - Giving insight to healthcare providers and hospitals about where patients seek care for concussion and their recovery needs.¹¹
-

Insurance factors into the level and type of healthcare received for all US residents. The **All-payer claims database (APCD) systems** are large State databases that include medical claims, pharmacy claims, dental claims, and eligibility and provider files collected from private and public payers. APCD data are reported directly by insurers to States, usually as part of a State mandate. APCD data includes: information on private insurance; data from most or all insurance companies operating in any State; and information on care for patients across care sites, rather than just hospitalizations and emergency department visits maintained by most states. They also include large sample sizes, geographic representation, and capture of longitudinal information on a wide range of individual patients.



There is national and local momentum to establish and implement APCDs. To date, 18 States have legislation mandating the creation and use of APCDs or are actively establishing APCDs, and more than 30 States maintain, are developing, or have a strong interest in developing an APCD.¹²

Conclusions

States seeking to establish a registry must be diligent, organized and collaborative to draft legislation, secure strong partners, and write protocols. States must manage records and connect people to the services they need while ensuring sufficient capacity to support services. Registries require hard work, staff effort, significant analysis, multiple partners, and funding sources to be optimally successful.

Issues arise with data collection, changes in regulations regarding coding, and shifts in technology systems. States must be prepared to solve these issues and accurately report on collection, demographics, causes, areas, and individuals most highly impacted. However, given all these efforts, when successful, registries can “make data sing” (Kinde & Roesler, 2021) by painting an accurate picture of the nature and prevalence of a chronic condition with lifelong challenges and support needs. States can also support residents with TBI that require these supports to be successful. Collectively, states can contribute to the national picture of TBI, and help to better determine trends and best practices in data collection, service delivery and prevention.

Connecting People to Services: A Personal Story

At the age of 21, Ann Smith sustained a TBI in a car crash, and was unconscious when EMT staff arrived. She was taken by ambulance to a local emergency department and then admitted to the hospital due to significant injuries. Ann remained unconscious for several days, and once awake remained in the hospital receiving acute, post-acute and rehabilitative care. While in the hospital, Ann and her family were told she had a moderate TBI and would need some cognitive and community supports when she returned home. She was given information about her injury, possible challenges and a factsheet outlining services she could access. She was discharged after a five- week length of stay to live temporarily with her parents. Once at home, Ann received a letter describing the same services shared at the hospital and after considering it, she and her family contacted the number given in the letter to ask about services and to describe her challenges and needs. TBI staff listened to her describe her current situation and discussed some possible options for home care coordination, assessment and cognitive remediation, and assistance with daily living skills building. Ann contacted the services shared with her and received further feedback, education and services. With extensive guidance and planning, she was then able to continue to recover, strengthen her physical and cognitive deficits and eventually return to college. From there, she secured a job with the help of staff skilled in supporting her job search, interviewing process and employment. She continued to receive encouragement and support while working as was able to maintain employment and live independently.

Summary of State Approaches

The Data workgroup conducted a survey to better understand and compile information regarding TBI Registries. Responses from this survey are shared below. As a reminder, the Data group has defined a TBI Registry as “any mechanism used by a Lead State Agency (or representative) to collect data on individuals living with brain injury for the purpose of surveillance or to ‘connect people to services’.” This could have included data collected from a state trauma registry or hospital association.

All states were asked **to respond, even if they did not have an active registry.** The survey included questions around registry history, operations, data, outreach, and reporting. Almost all the ACL TBI grantees responded, and an additional two states not currently funded also responded:

State	Current Grantee	Registry	Link
Alabama	Yes	Yes	https://www.alabamapublichealth.gov/atr/index.html
Alaska	Yes	Yes	http://dhss.alaska.gov/dph/Emergency/Pages/trauma/registry.aspx
Arkansas	Yes	Yes	https://atrp.ar.gov/wp-content/uploads/sites/24/2018/08/TBI-Registry-Referral-Process.pdf
California	Yes	No	
Colorado	Yes	Yes	https://cdphe.colorado.gov/emergency-care/trauma/colorado-trauma-registry
Georgia	Yes	Yes	https://dph.georgia.gov/georgia-central-trauma-registry
Idaho	Yes	Yes	https://idahotseregistry.org/index.php
Indiana	Yes	Yes	https://www.in.gov/isdh/19540.htm
Iowa	Yes	Yes	https://idph.iowa.gov/brain-injuries/surveillance-and-reporting
Kansas	Yes	No	http://www.kstrauma.org/trauma_guidance.htm
Kentucky	Yes	Yes	https://lern.la.gov/trauma/trauma-registry/
Maine	Yes	No	
Maryland	Yes	Yes	https://law.justia.com/codes/maryland/2013/article-ghg/section-20-108/
Massachusetts	Yes	Yes	https://www.mass.gov/service-details/state-trauma-registry-data-submission
Minnesota	Yes	Yes	https://www.health.state.mn.us/facilities/traumasystem/mntrauma/index.html
Missouri	Yes	Yes	https://health.mo.gov/data/headspinalcordinjury/index.php

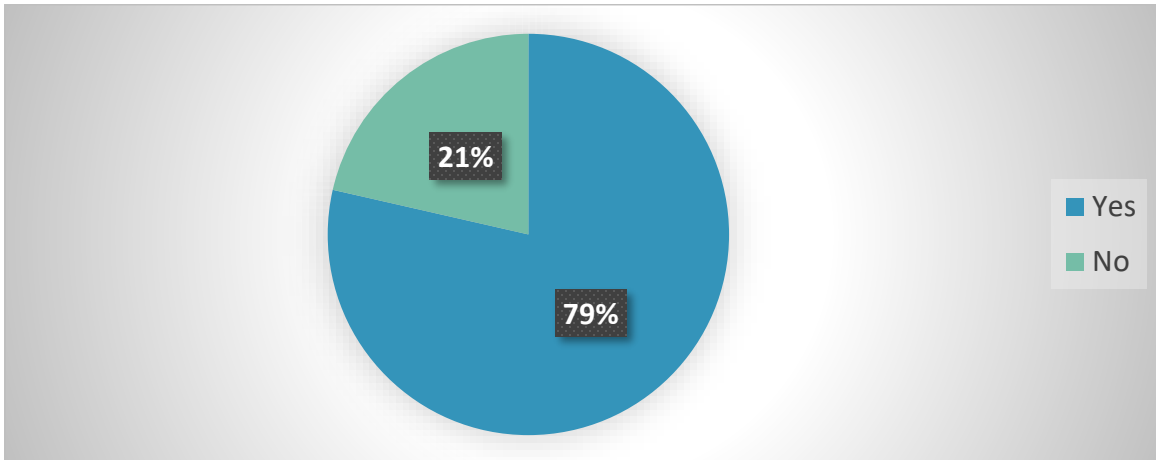
Nebraska	Yes	Yes	https://braininjury.nebraska.gov/resources/brain-injury-data-and-statistics
North Carolina	Yes	Yes	https://info.ncdhhs.gov/dhsr/EMS/trauma/traumaregistry.html
Ohio	Yes	No	
Oregon	Yes	Yes	https://www.oregon.gov/oha/PH/ProviderPartnerResources/EMSTraumaSystems/TraumaSystems/Pages/registry.aspx
Pennsylvania	Yes	No	
Rhode Island	Yes	Yes	https://health.ri.gov/programs/detail.php?pgm_id=34
Tennessee	Yes	Yes	https://www.tn.gov/health/health-program-areas/health-professional-boards/ems-board/ems-board/trauma.html
Utah	Yes	Yes	http://www.utahtrauma.org/
Vermont	Yes	No	
Virginia	Yes	Yes	https://www.vdh.virginia.gov/emergency-medical-services/trauma-critical-care/virginia-statewide-trauma-registry/
West Virginia	Yes	Yes	http://www.tbi.cedwvu.org/tbi-at-a-glance/wv-tbi-registry/
Arizona	No	Yes	https://atrp.ar.gov/about/
North Dakota	No	No	

Additionally, there are other states who have registries that did not respond to the survey. Further information can be found in the Literature Review reference within the *additional resources* section.

Questionnaire Responses

A copy of the questionnaire is included in the *additional resources* section. General comments regarding each question are included below the chart.

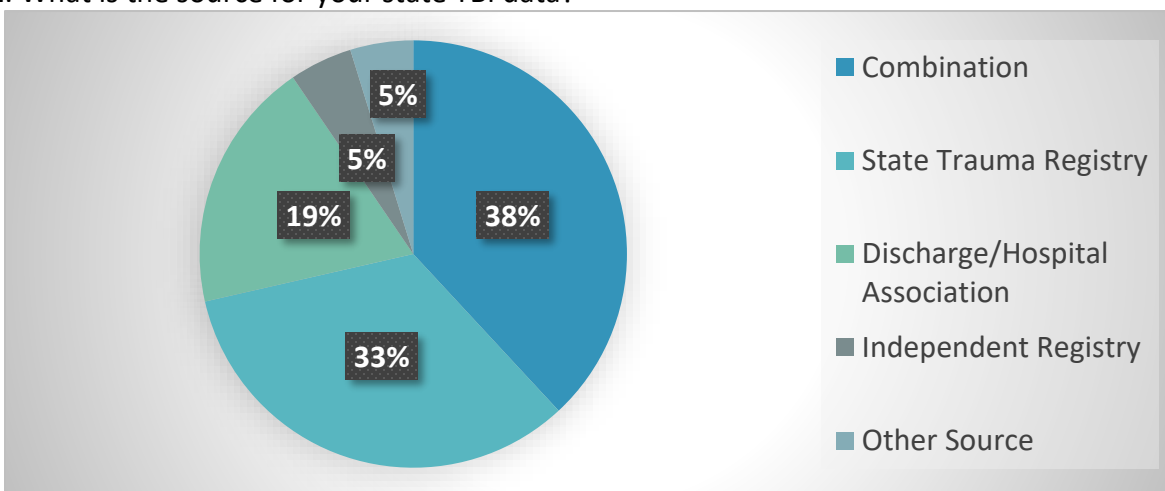
Q1. Does your state have an established process for TBI data collection (e.g., TBI Registry, Trauma Registry, Hospital Association data)?



States with no registries reported a need for data collection to be more cohesive, consistent and integrated across agencies and programs. They also reported denied state attempts to create legislation for surveillance. Some states report adding screening questions to other data mechanisms, such as: Behavioral Risk Factor Surveillance System (BRFSS); Long-Term Care systems; and school system concussion data collection.

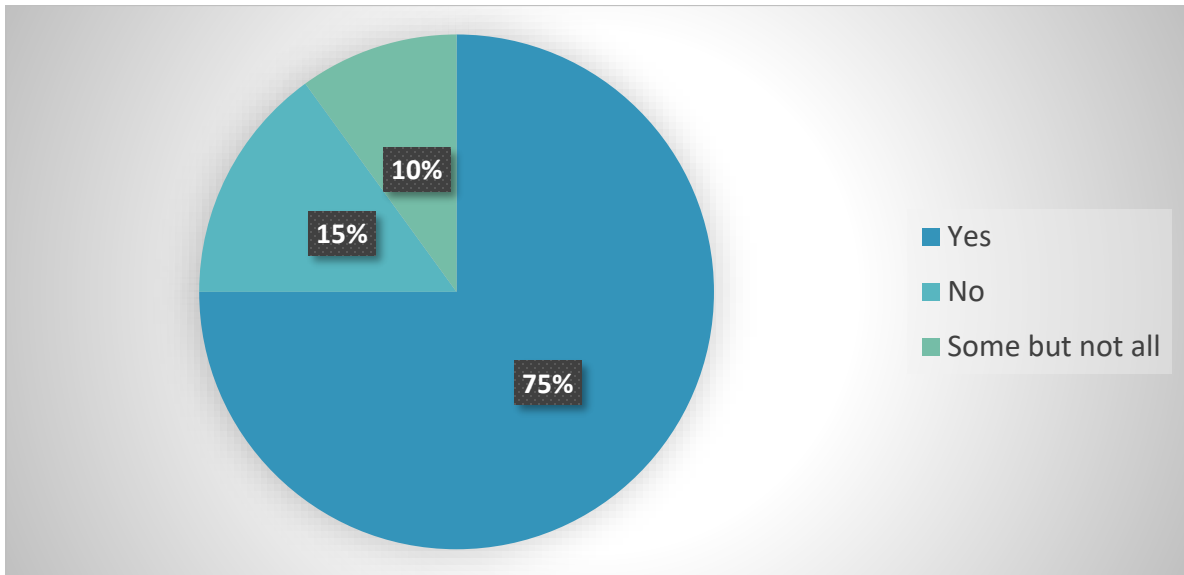
Registry Data

Q2. What is the source for your state TBI data?



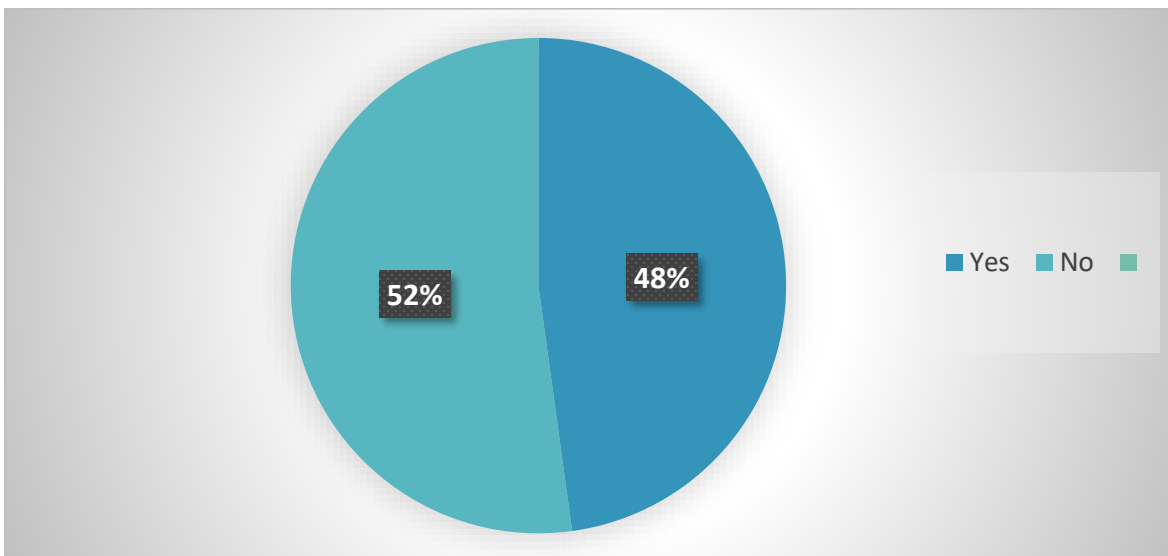
Other data sets states utilize included: Office of Highway Safety; EMS records; Vital Records; mortality data; and TBI Model Systems Prevalence data.

Q3. Do you have an agreement in place to access the TBI data source(s) selected above?



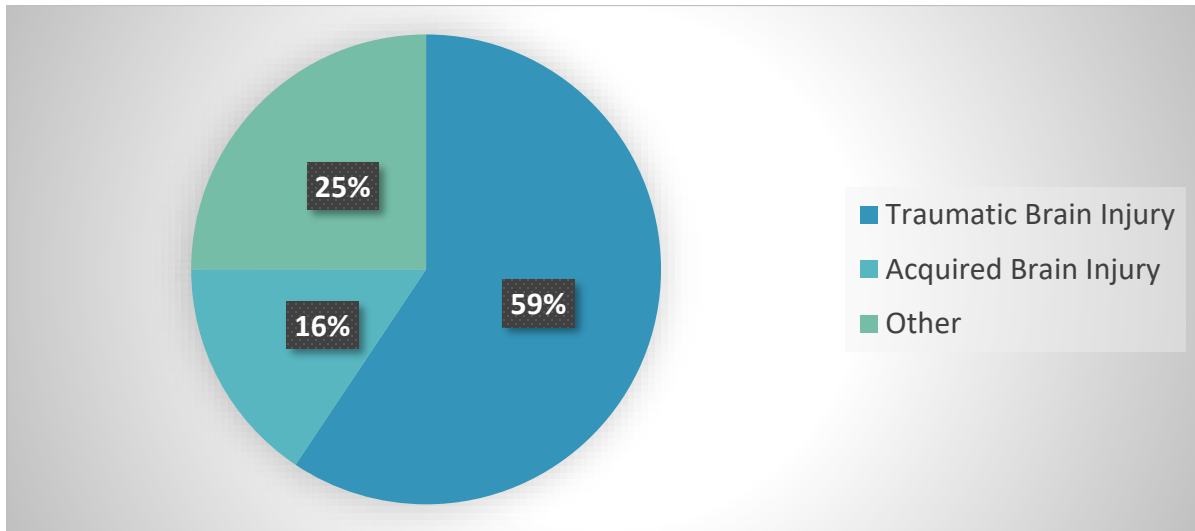
States have a variety of agreement types. Most states work through departments of health and several involve the state hospital association and have some level of legislation securing access.

Q4. Does your state TBI registry use data to link people to services?



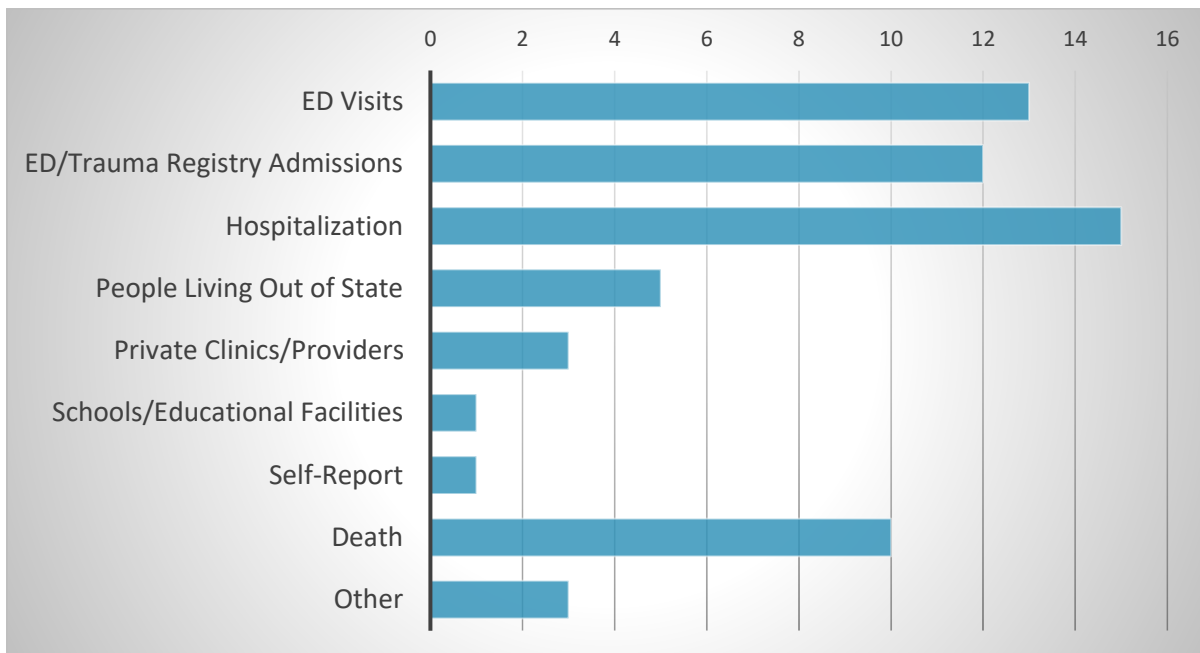
Some states are in the process of enhancing registry surveillance to also include connection to services. Other states have other measures in place for outreach.

Q5. What is the focus of data collection for your registry?



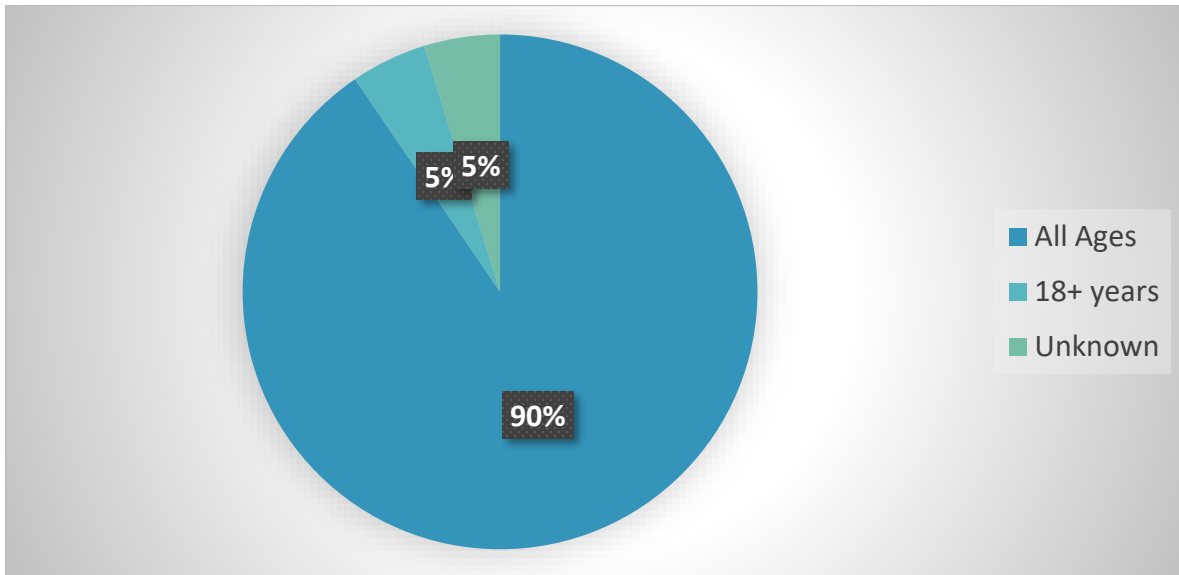
States selecting "other" reported gathering data on spinal cord injury, heart disease, and general trauma.

Q6. Which of the following are included in your TBI Registry data set?



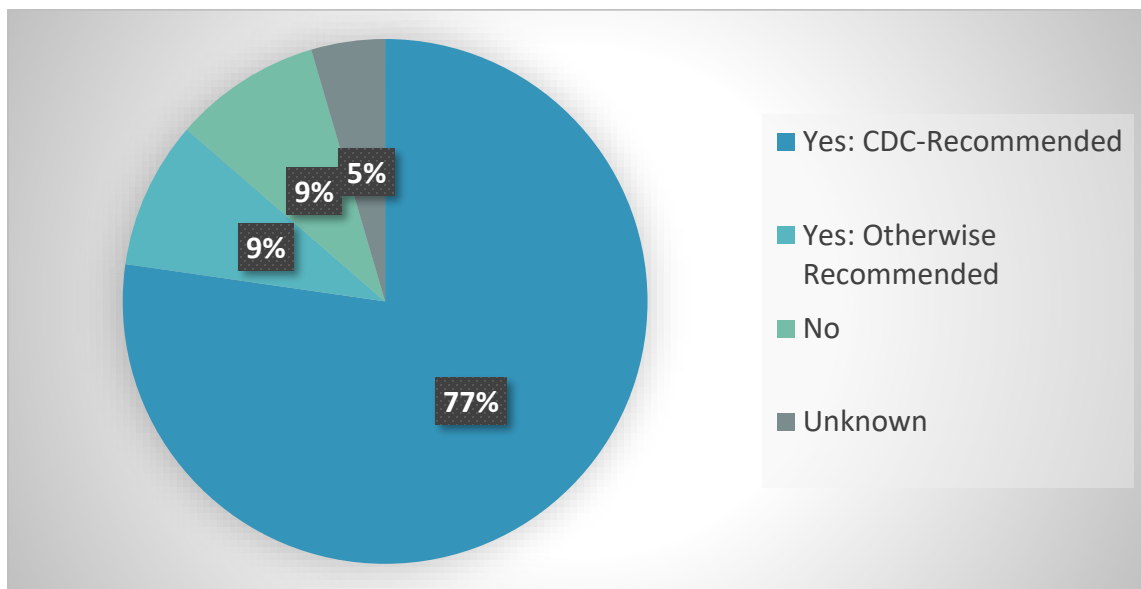
States with registries include several types of records, with the majority focused on hospital admissions.

Q7. Which age groups are included in your TBI Registry?



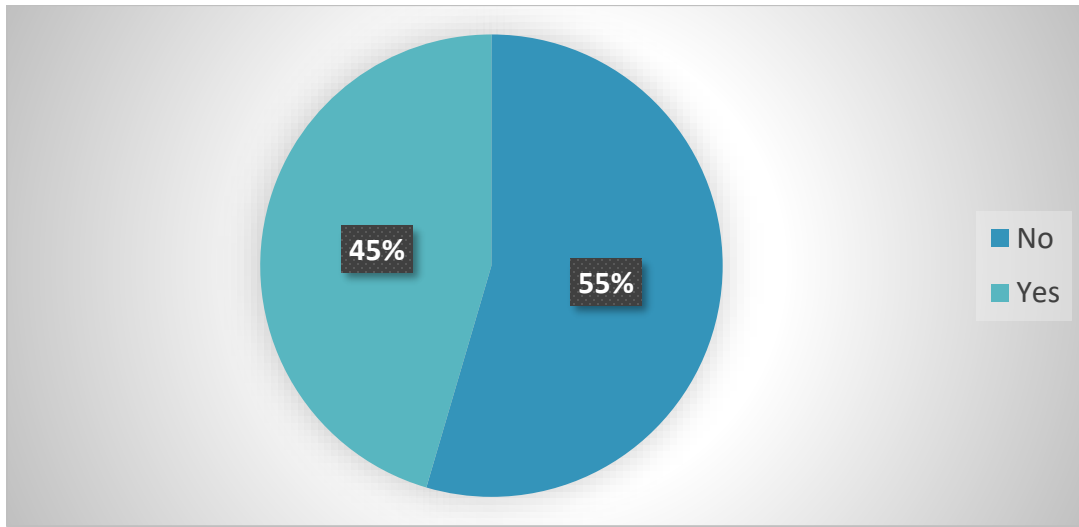
While many states collect data related to children and youth, few are linked to services. There has been much discussion about the need for pediatric registries within and across states.

Q8. Does your state use ICD-10 codes for inclusion criteria to collect TBI or Trauma registry data?



A few states do not have any specifications in legislation and use data that is accessible.

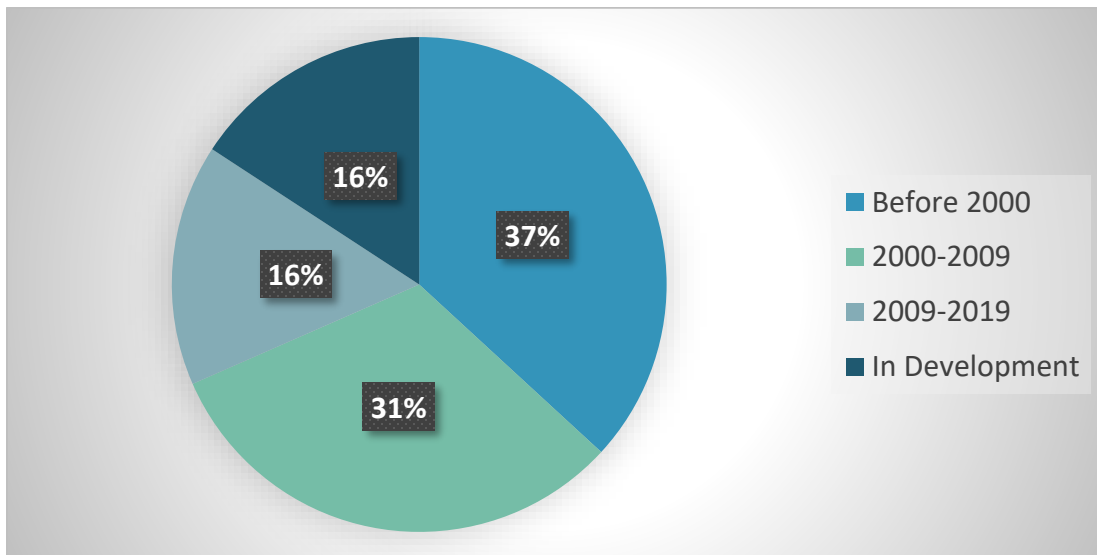
Q9. Do you include/download the unspecified head-injury ICD-10 Code: S.09?



States who do not include this code due to billing and/or reimbursement stipulations, Lack in specificity for head injury, and the possibility that this code might not include brain injury (more likely to be used for superficial injury).

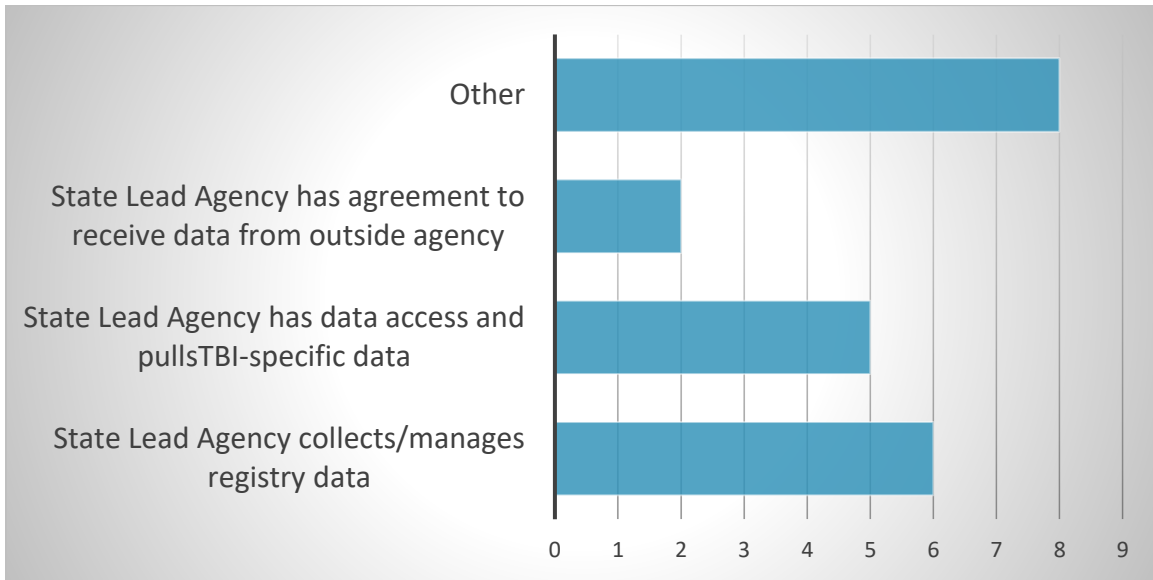
Registry History

Q10. What year was your TBI registry established?



With two exceptions, states who reported having established registries reported accomplishing this effort through legislation.

Q11. What is your state's relationship to the TBI Registry?

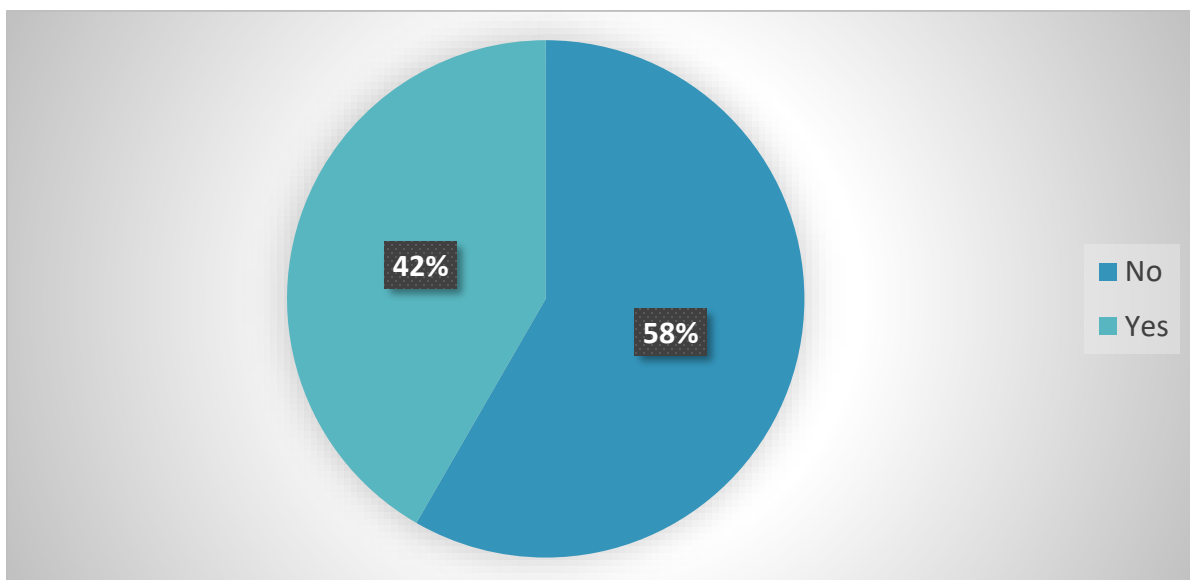


For states answering "other", the majority did not have a registry in place.

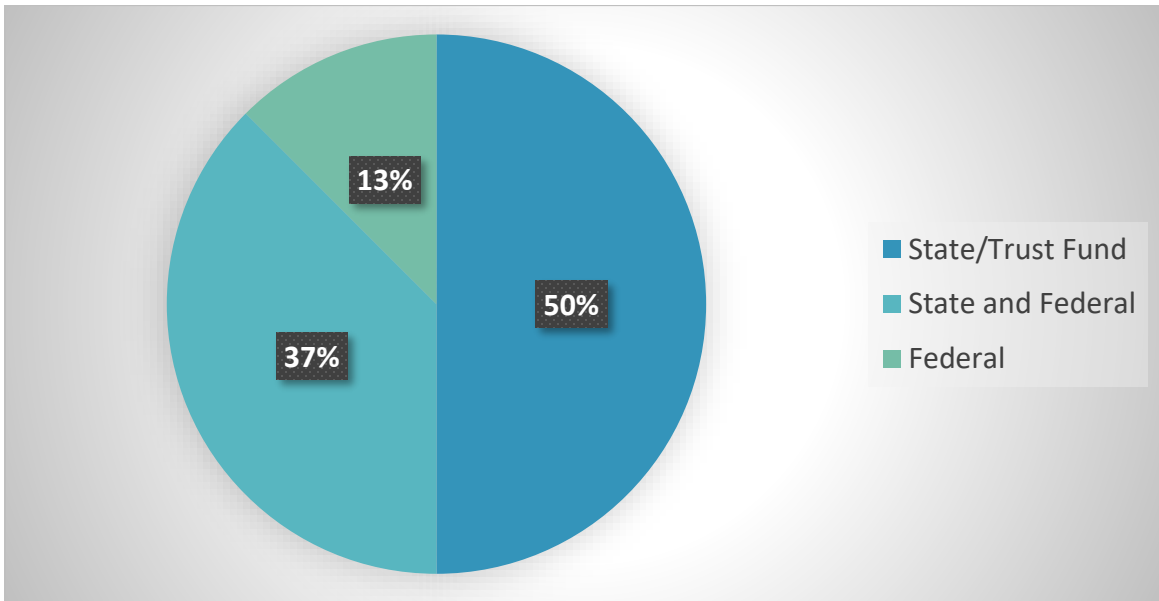
Q12. How many staff are required to manage your registry?

Although the number of staff varied across states, from 0 to more than 6, none of the states reported requiring the equivalent of more than 1 FTE.

Q13. Is your registry funded?

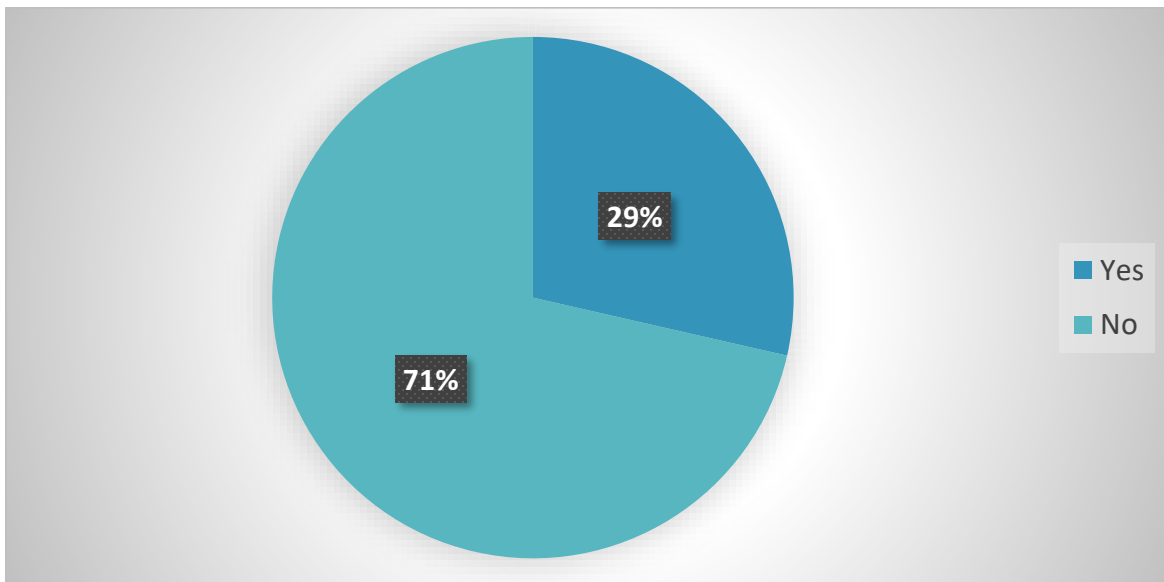


Q14. If funded, what is the source of funding?

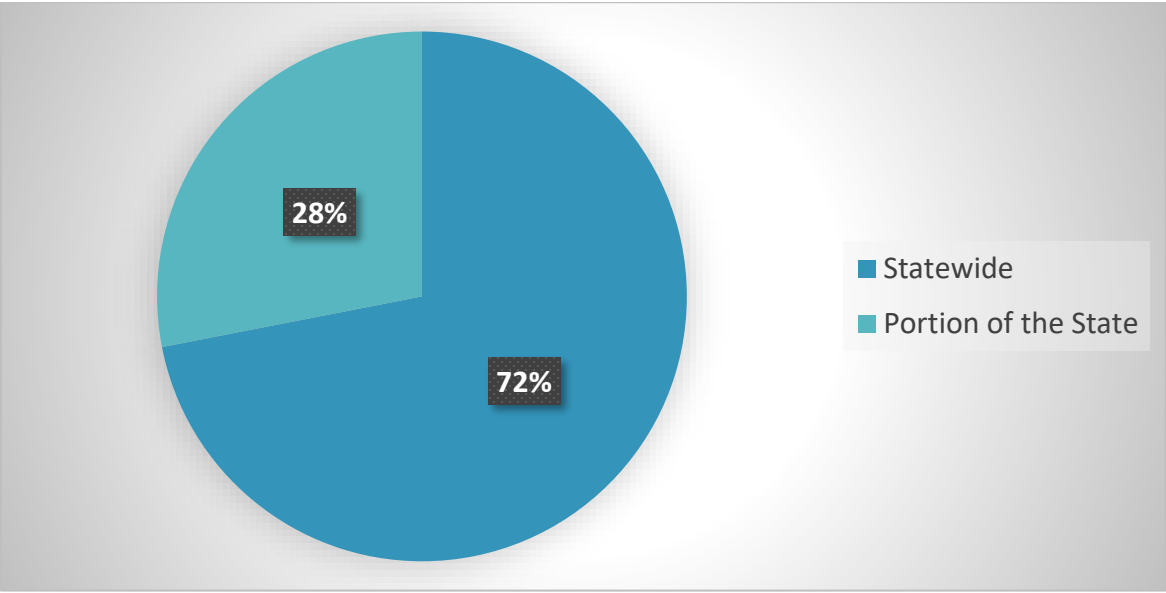


Unfortunately, the amount of funding is largely unknown.

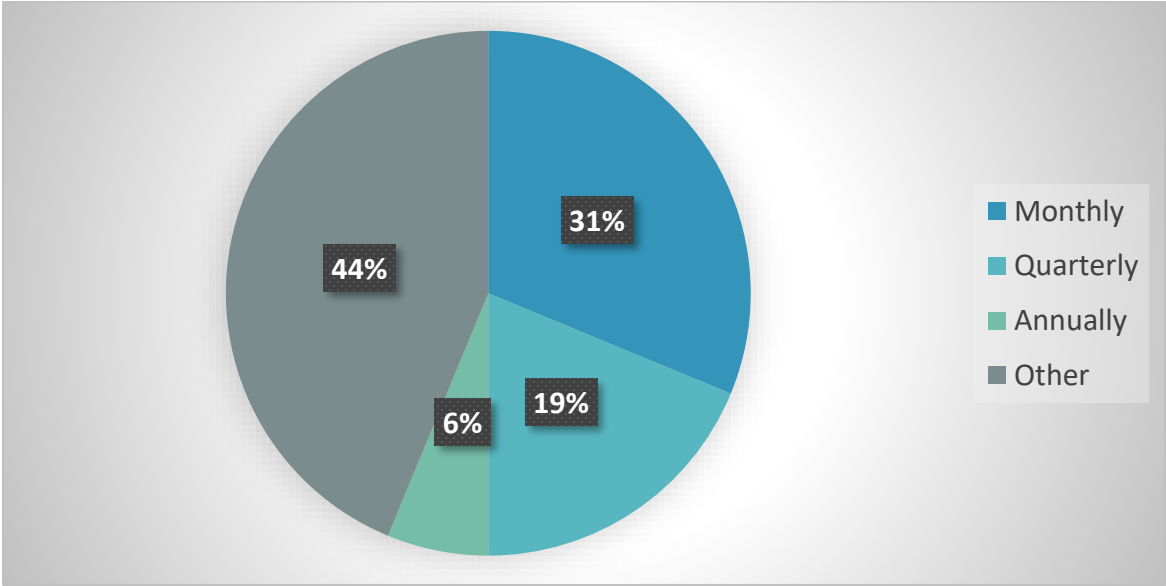
Q15. Does your state receive funding from the Centers for Disease Control (CDC) to systematically collect data on TBI incidence?



Q16. Is the registry statewide, only a portion of the state, or only a portion of the hospitals across the state?

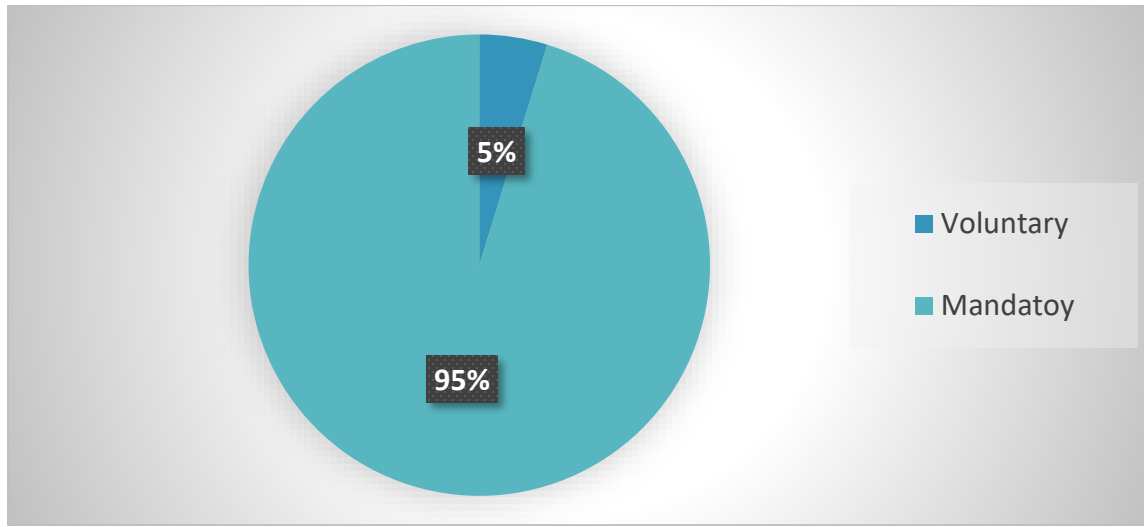


Q17. How often is data downloaded?



For states who responded 'other', most states responded that data was downloaded more frequently, even daily, or that the consistency of the download varied.

Q18. Are hospitals or other units required to submit data or do they contribute voluntarily?

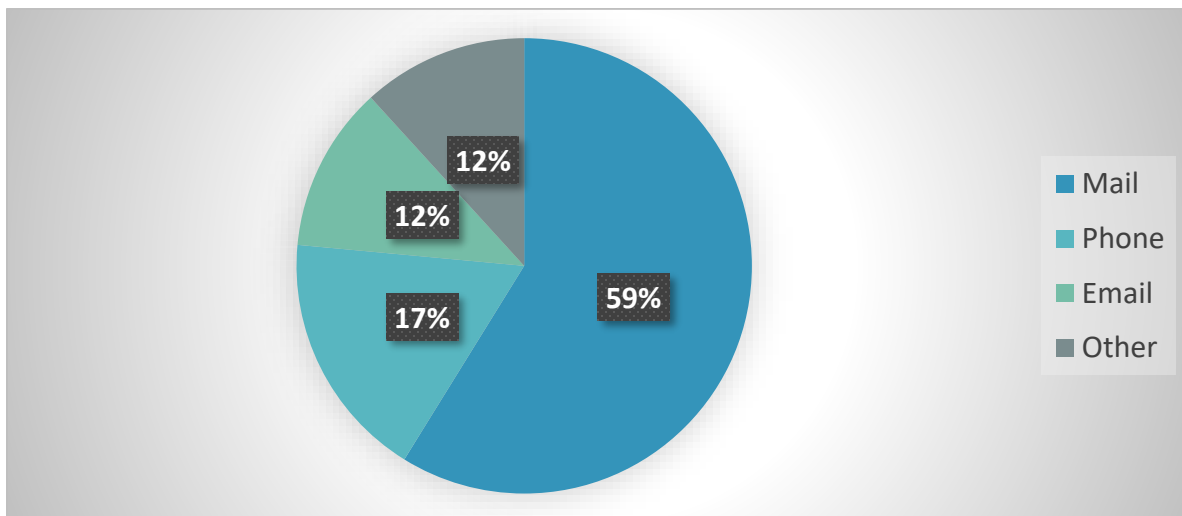


Even with mandatory data submission, states report it challenging to maintain consistency with receipt of data if coming from an outside agency. Data is shared but not regularly or is delayed in transfer. This may be due to several reasons: hospital staff turnover; changes/issues with reporting mechanisms; a lack of program or financial consequence for non-compliance.

Registry Outreach

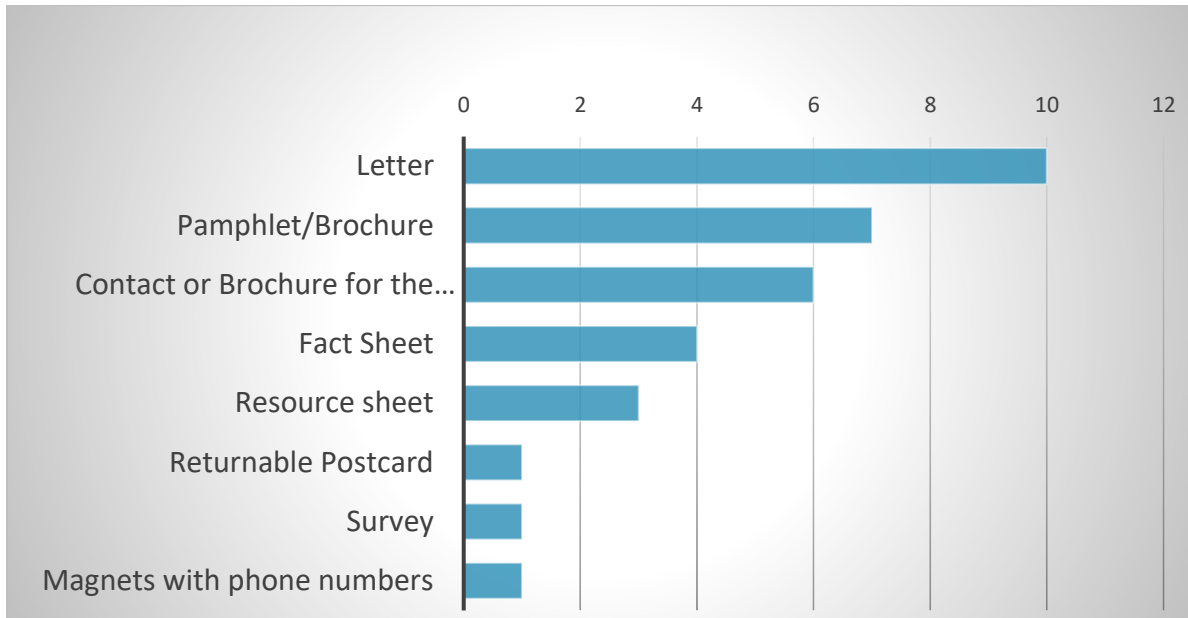
For this questionnaire and Guide, outreach is defined as any mechanism used by state Lead Agencies to use TBI Registry data to connect people living with TBI to services and/or supports.

Q19. How is the TBI Registry outreach conducted?

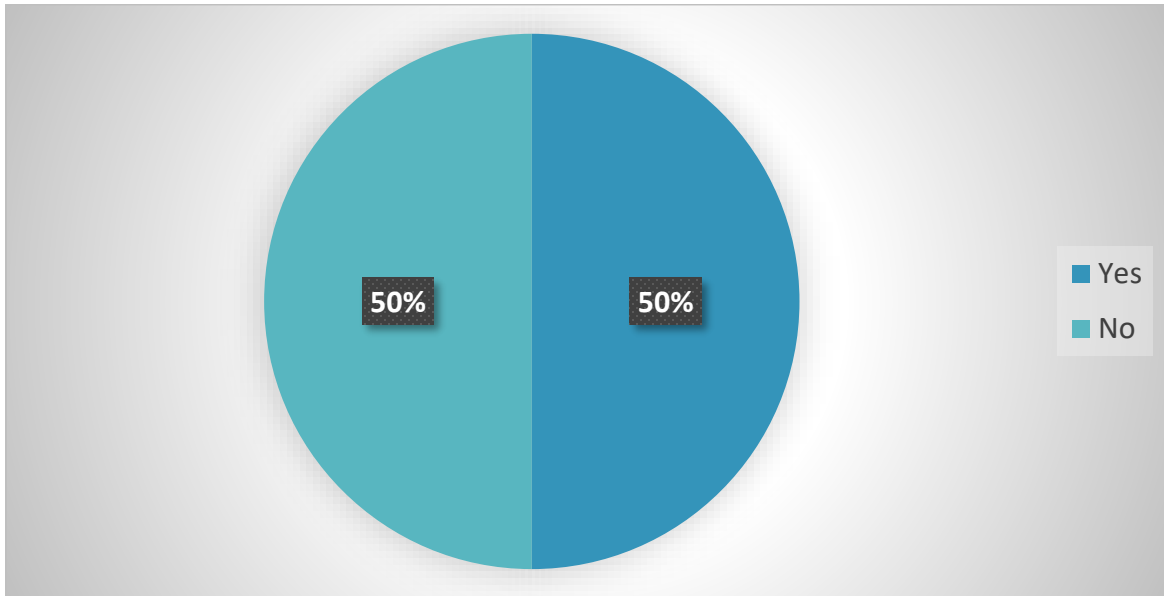


States selecting 'other' report utilizing the lead agency or other website, or public events for outreach. It is interesting to note whether any states use a combination of these methods, and if it proves to increase efforts.

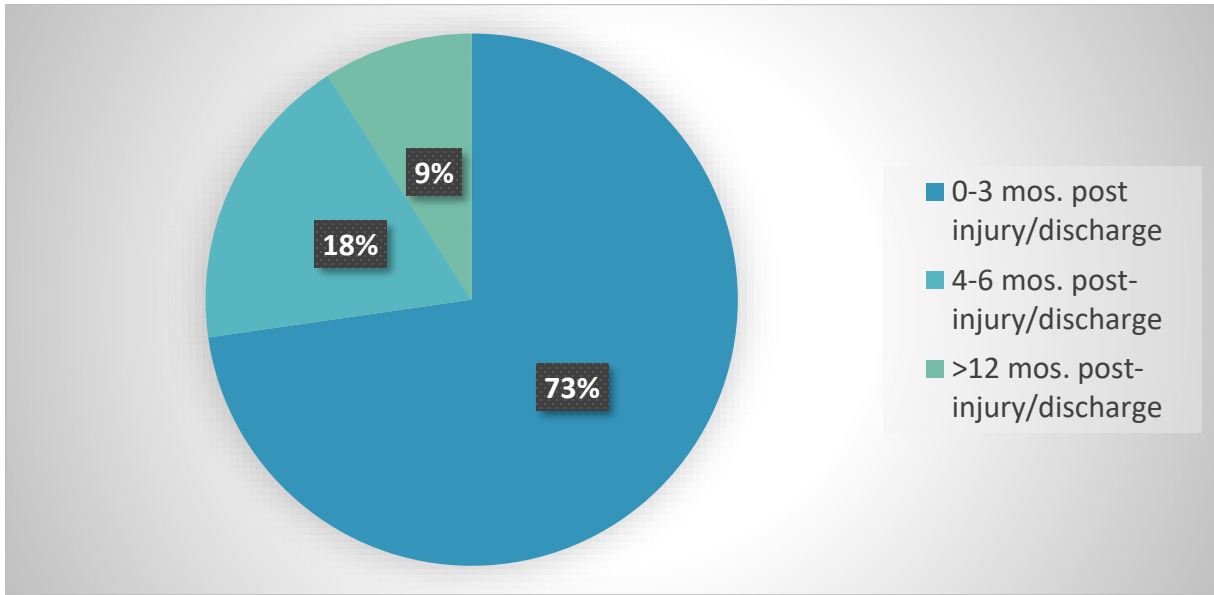
Q20. What information is provided during outreach?



Q21. Is a case manager or resource facilitator assigned?

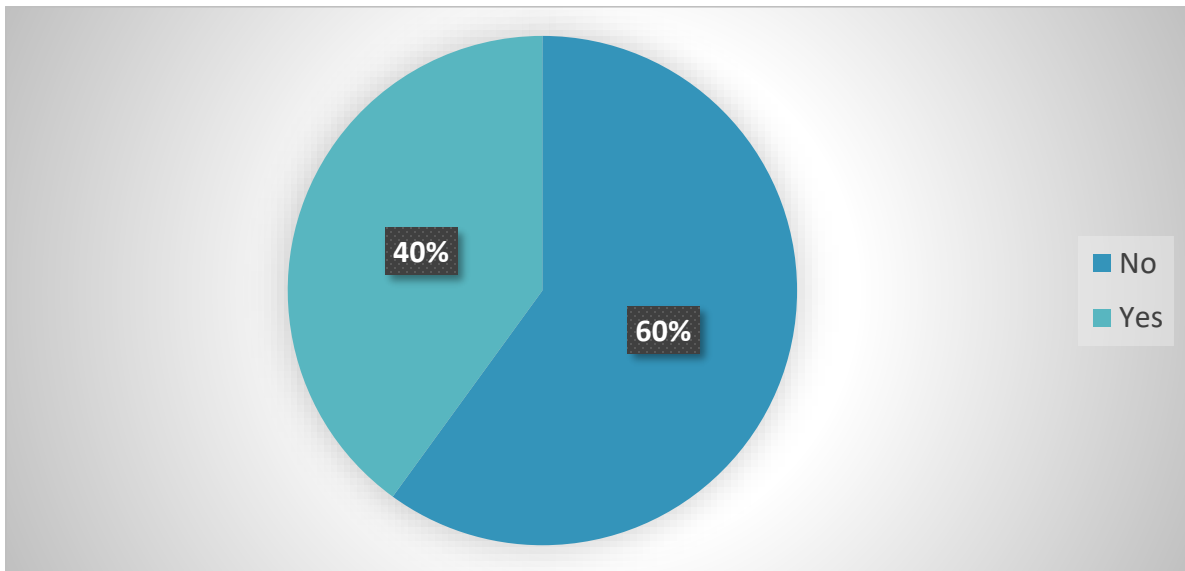


Q22. What is the expected time frame for contacting the person living with brain injury for purposes of connecting them to services?



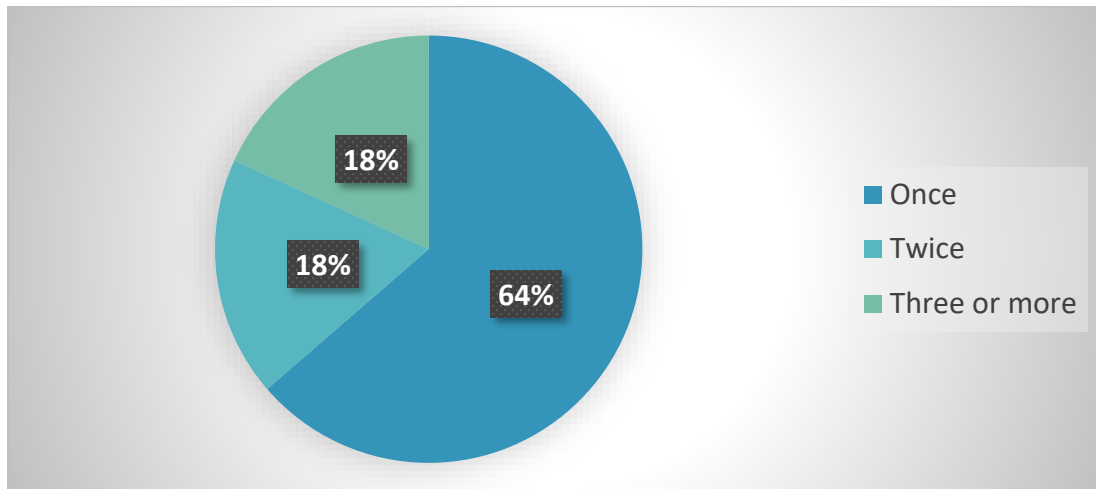
Is there an optimal time for contact? Should multiple points of outreach be the standard?

Q23. Is everyone in the registry eligible to be contacted?

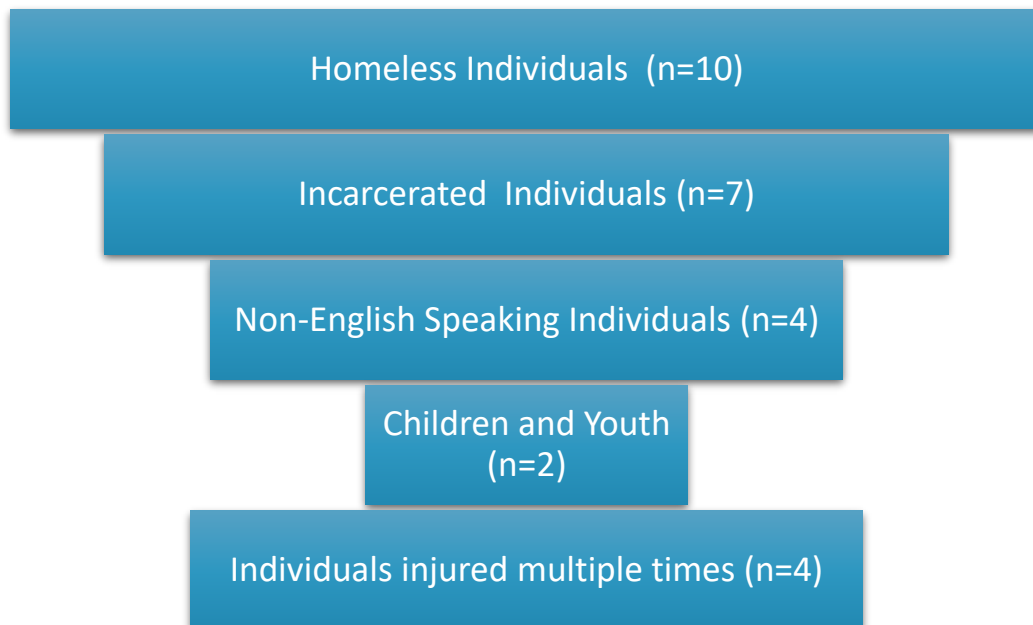


States responding with 'no' reported eliminating from contact those who are deceased, homeless, incarcerated, out-of-state residents, or those with mild TBI. Records are still reported in terms of incidence, however.

Q24. How frequently is the person living with brain injury contacted for purposes of linking them to services?



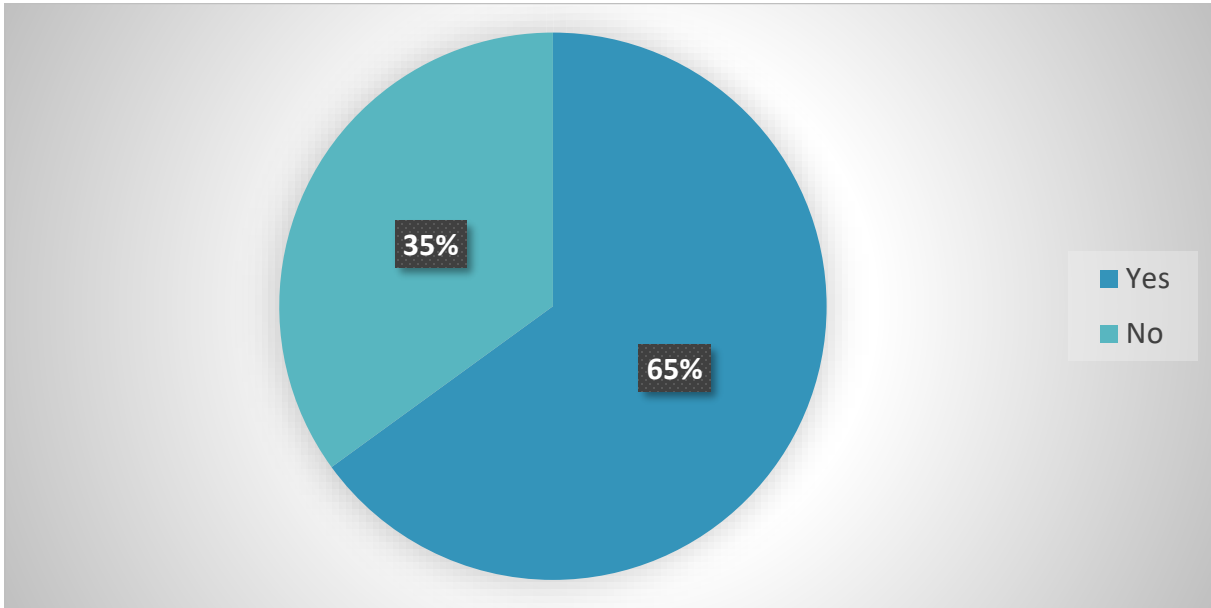
Q25. Does your state have challenges reaching certain populations to do TBI Outreach?



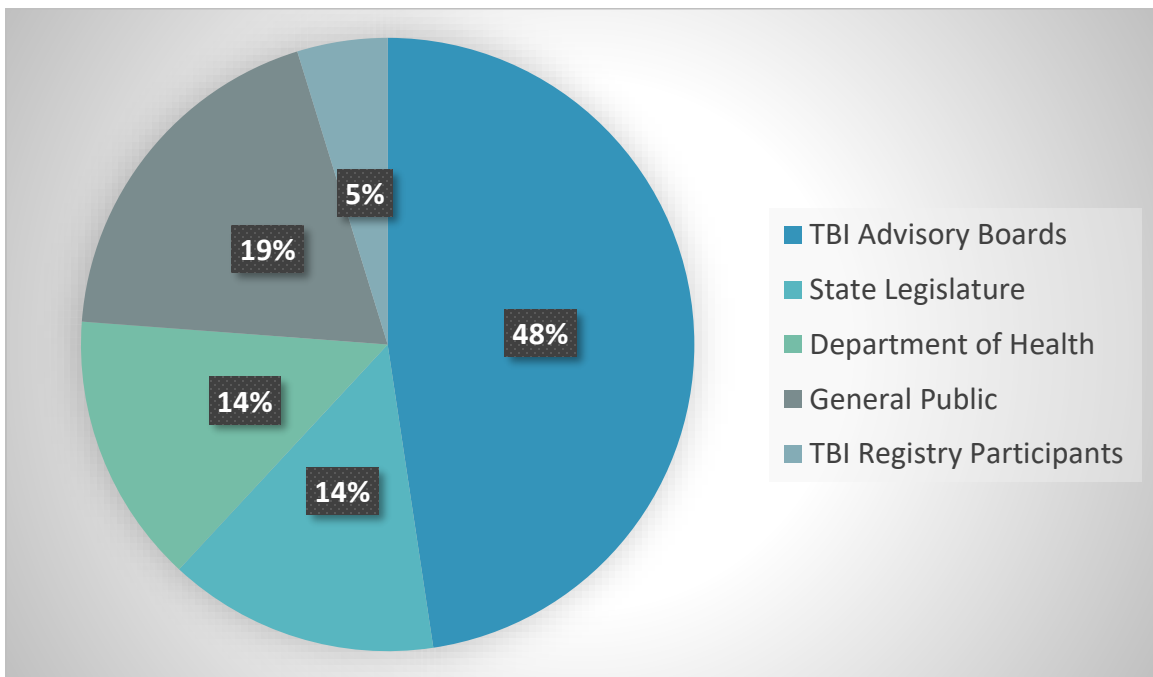
Many states have outreach issues related to registry contact with these populations. Some states work to increase outreach effectiveness by providing age-specific contact information or contact information in alternative formats and languages. Vulnerable populations with the justice system or who experience homelessness without a discharge to home or with a permanent address might be ineligible for contact. Other options for outreach rather than through a traditional registry process are sometimes applied.

Registry/Data Reporting

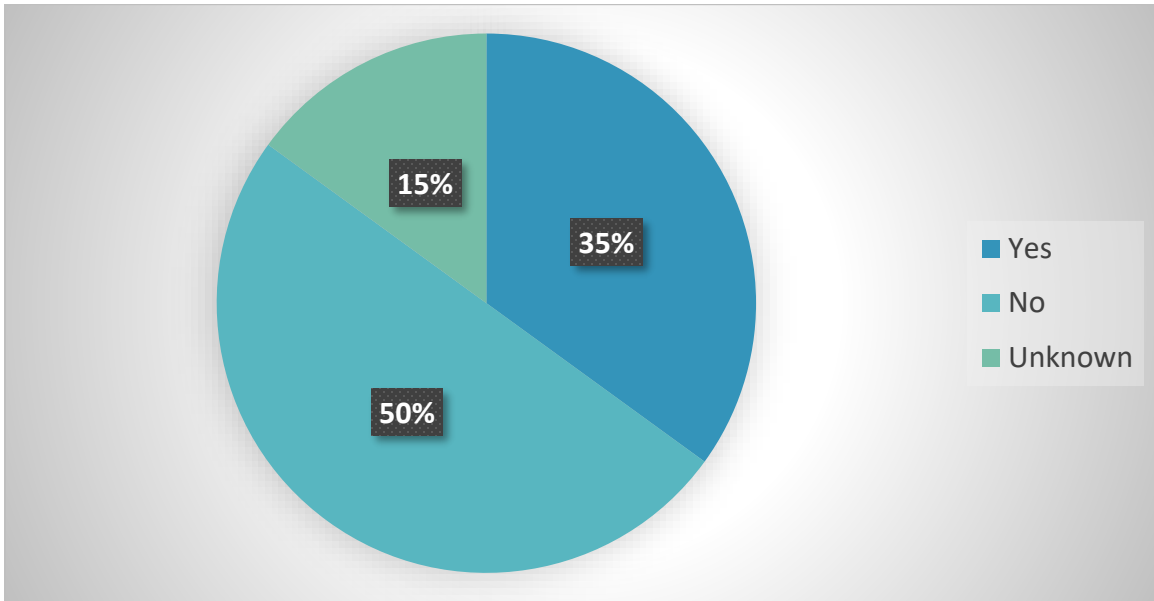
Q26. Is TBI registry data analyzed and aggregated into a report by the Lead Agency?



Q27. Who receives Registry Reports?



Q28. Does your Lead Agency or their partners collect additional data from individuals on the registry?



Additional information collected by states included surveys gathering additional demographics or interest in resources, diagnoses, financial resources, payor source, referrals, requests, assessments, services, conducted after outreach and contact.

References

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8. Division of Adolescent and School Health, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention: <https://www.cdc.gov/healthyouth/data/yrbs/overview.htm>; August 2020.
9. U.S. Department of Veterans Affairs: <https://www.publichealth.va.gov/epidemiology/reports/oefoifond/health-care-utilization/tbi-registry.asp>; August 2020.
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National Association of State Directors of Developmental Disabilities Services and HSRI: <https://www.nationalcoreindicators.org/about/history/>; 2021.
11. Centers for Disease Control and Prevention, National Center for Injury Prevention and Control: <https://www.cdc.gov/traumaticbraininjury/ncss/index.html>; March 2019.
12. Agency for Healthcare Research and Quality: All-Payer Claims Databases: <https://www.ahrq.gov/data/apcd/index.html>; February 2018.

Additional Resources

These resources can be accessed below or through the workgroup or online at www.nashia.org:

1. Questionnaire: Using Data to Connect People to Service workgroup
2. Data Elements/Dictionary Data Dictionary Sample: Idaho TSE Registry
<https://www.idahotseregistry.org/dataspecifications.php>
3. Sample Data Sharing Agreement: Alabama Department of Rehabilitation Services/Alabama Department of Public Health
4. Sample contact letter: Virginia Department of Aging and Rehabilitative Services/Brain Injury Association of Virginia
5. Literature Review: Human Services Research Institute