## HAVANA SYNDROME

# Better Patient Communication and Monitoring of Key DOD Tasks Needed to Better Ensure Timely Treatment



Report to Congressional Committees

July 2024 GAO-24-106593 United States Government Accountability Office

Accessible Version

## **GAO Highlights**

View GAO-24-106593. For more information, contact Kimberly Gianopoulos at 202-512-8612 or GianopoulosK@gao.gov. Highlights of GAO-24-106593, a report to congressional committees

**July 2024** 

### HAVANA SYNDROME

## Better Patient Communication and Monitoring of Key DOD Tasks Needed to Better Ensure Timely Treatment

### Why GAO Did This Study

In 2016, Department of State staff at the U.S. Embassy in Havana, Cuba, began experiencing a sudden onset of symptoms, usually following a loud sound. These included head pain, tinnitus, vision problems, vertigo, and cognitive difficulties. These events, first labeled "Havana Syndrome," are now referred to as AHIs and have affected employees (and their families) of various federal agencies overseas and domestically. Federal law requires DOD to provide treatment to U.S. government employees (current and former) and their family members diagnosed with AHI conditions or related afflictions at an appropriate military treatment facility.

GAO was asked to review DOD's efforts to facilitate AHI patients' access to the MHS and develop an AHI Registry. This report examines (1) the challenges AHI patients have faced accessing care in the MHS, (2) how DOD is facilitating AHI patients' access to the MHS, and (3) the extent to which DOD has developed a registry to facilitate AHI research. GAO reviewed DOD planning documents and interviewed officials. GAO also interviewed, both in-person and virtually, 65 AHI patients from various federal entities on their experiences accessing the MHS.

#### What GAO Recommends

GAO is making six recommendations to DOD, including that DOD develop written guidance, establish a mechanism for official communication with AHI patients, implement its AHI care cell, monitor initiatives, and create a plan to gather registry consent from patients who have left the MHS. DOD concurred with the recommendations.

#### What GAO Found

U.S. government employees and family members in several countries have experienced a sudden onset of symptoms referred to as anomalous health incidents (AHI). GAO interviewed 65 AHI patients, who reported a variety of challenges in accessing the Military Health System (MHS). They included inconsistent support from home agencies before seeking MHS treatment, limited information and unclear points of contact upon entering the MHS, and difficulty scheduling appointments when using the MHS. According to officials, civilian AHI patients are not as familiar with the MHS as active-duty military and need additional support to navigate the system. In addition, the Department of Defense (DOD) lacks an official mechanism to communicate authoritative information to AHI patients, which led some to use informal support groups to navigate the MHS. While some patients found these groups valuable, other patients and DOD officials noted these groups sometimes communicated inaccurate information. For example, some officials reported misinformation in the groups about the availability of appointments in the MHS. Without an official DOD mechanism to communicate with AHI patients, this situation can perpetuate inaccuracies, fuel perceptions of inequity, and lessen trust in MHS providers.

#### Challenges Reported by Anomalous Health Incident Patients Accessing the Military Health System











benefit information







Source: GAO patient interviews; GAO (icons). | GAO-24-106593

DOD has created a plan to address some access concerns of AHI patients, but it contains uncertain timeframes and lacks monitoring provisions. For example, the plan produced a new approval process for AHI patients to enter the MHS and calls for an enhanced AHI Care Coordination Cell to centralize administrative and clinical processes. However, the timeframe for implementing the care cell has been delayed. Moreover, the plan does not contain components for monitoring these two key tasks, which could undercut its success.

DOD has developed a registry as required by law to include certain data on AHI patients assessed or treated by DOD. However, the AHI Registry data fields remain under development. Moreover, delays in obtaining individual consent for inclusion have limited the number of patients contained in the AHI Registry. DOD did not initially seek consent from individuals to be included in the registry when they entered the MHS, limiting the number of participants. Of 334 AHI patients who had qualified for care in the MHS in January 2024, only 33 had been entered in the AHI Registry as of May 2024. According to DOD, key agencies also have not signed memorandums of agreement with DOD, which has contributed to the slow inclusion of AHI patients. Without a plan to gather consent from AHI patients who have left the MHS, DOD will have a limited number of patients in the AHI Registry to analyze, which could limit its usefulness for supporting AHI analysis and research activities.

## Contents

GAO Highlights	ii
Why GAO Did This Study	ii
What GAO Recommends	ii
What GAO Found	ii
Letter 1	
Background	3
AHI Patients Face Several Challenges Accessing Care in the Military Health System	12
DOD Plan for Facilitating AHI Care Contains Uncertain Timeframes and Lacks Monitoring Provisions	22
AHI Registry Remains Under Development and Delays in Obtaining Consent Have Limited its Usefulne	ss 27
Conclusion 30	
Recommendations for Executive Action	30
Agency Comments	31
Appendix I Objectives, Scope, and Methodology	32
Appendix II Comments from the U.S. Department of Defense	34
Accessible Text for Appendix II Comments from the U.S. Department of De 38	fense
Appendix III GAO Contact and Staff Acknowledgments	42
Tables	
Table 1: Department of Defense Secretarial Designee Processing Times by Calendar Year	9
Table 2: Department of Defense (DOD) Plan of Action and Milestones Tasks with Projected Completion Dates for Anomalous Health Incidents (AHI) Care	25
Figures	
Challenges Reported by Anomalous Health Incident Patients Accessing the Military Health System	iii
Figure 1: Defense Intrepid Network for Traumatic Brain Injury and Brain Health Locations	6
Accessible Text for Figure 1: Defense Intrepid Network for Traumatic Brain Injury and Brain Health Locations	6
Figure 2: Anomalous Health Incident Secretarial Designees by Agency as of April 2024	8
Accessible Data for Figure 2: Anomalous Health Incident Secretarial Designees by Agency as of April 2	0248
Figure 3: Intended Secretarial Designee Approval Timeline for Anomalous Health Incident Patients	9
Figure 4: Secretarial Designee Package Approvals by Month	10

Accessible Data fo	r Figure 4: Secretarial	Designee Packag	ae Approvals b	v Month
	<u> </u>		, , , , , , , , , , , , , , , , , , , ,	,

Figure 5: Agency Breakdown of Anomalous Health Incident Patients Interviewed by GAO

1012

Accessible Data for Figure 5: Agency Breakdown of Anomalous Health Incident Patients Interviewed by GAO 12

Figure 6: Comparison of Department of Defense's Secretarial Designee Process with Section 732 Approval Process 24

**Abbreviations** 

AHI anomalous health incidents

ASD(HA) Assistant Secretary of Defense for Health Affairs

CFT cross-functional team

CNBHCP Coalition and Non-Beneficiary Health Care Programs

CPAP continuous positive airway pressure

DAD-MA/CSD Deputy Assistant Director, Medical Affairs, Clinical

**Support Division** 

DHA Defense Health Agency DOD Department of Defense

FY fiscal year

HAVANA Act Helping American Victims Afflicted by Neurological

Attacks Act of 2021

HA-CCO Health Affairs-Correspondence Control Office

NDAA National Defense Authorization Act

MHS Military Health System
MTF military treatment facility

NICoE National Intrepid Center of Excellence

OASD(HA) Office of the Assistant Secretary of Defense for Health

**Affairs** 

Plan of Action and Milestones

SECDES secretarial designee

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July 29, 2024

The Honorable Jack Reed Chairman The Honorable Roger F. Wicker Ranking Member Committee on Armed Services United States Senate

The Honorable Mark R. Warner Chairman The Honorable Marco Rubio Vice Chairman Select Committee on Intelligence United States Senate

In 2016, Department of State employees at the U.S Embassy in Havana, Cuba, began experiencing a sudden onset of symptoms. These included vertigo, imbalance, blurry vision, tinnitus, headache, hearing loss, nausea, and cognitive dysfunction. Although there are reports that predate these incidents, the media originally called these phenomena Havana Syndrome, as they were the first to garner public attention. Such events have affected U.S. government employees, military servicemembers, and their families in countries around the world, and are now referred to as anomalous health incidents (AHI) by the U.S. government. While the precise nature and causes of AHIs remain under investigation, medical researchers have noted that timely evaluation and treatment are essential to ensuring positive patient outcomes and for gathering useful data for further research.

Section 732 of the National Defense Authorization Act (NDAA) for Fiscal Year (FY) 2022 required the Department of Defense (DOD) to provide treatment to U.S. government employees and their family members diagnosed with AHI conditions or related afflictions at an appropriate military treatment facility (MTF), such as the National Intrepid Center of Excellence (NICoE) in Bethesda, Maryland, which specializes in traumatic brain injuries. Section 1044 of the FY 2023 NDAA amended section 732, expanding eligibility to "covered individuals" defined to include both current and former U.S. government employees and their family members. DOD has used the secretarial designee (SECDES) process to authorize access for non-military U.S.

<sup>&</sup>lt;sup>1</sup>National Defense Authorization Act for Fiscal Year 2022, Pub. L. No. 117-81, 135 Stat. 1541, 1797 (Dec. 27, 2021). The act required the Secretary of Defense to provide employees of the U.S. Government and their family members, who the Secretary determines are experiencing symptoms of certain anomalous health conditions, timely access for medical assessment, subject to space availability, to the National Intrepid Center of Excellence, an Intrepid Spirit Center, or an appropriate military medical treatment facility, as determined by the Secretary.

<sup>&</sup>lt;sup>2</sup>James M. Inhofe National Defense Authorization Act for Fiscal Year 2023, Pub. L. No. 117-263, 136 Stat. 2395, 2771-2 (Dec. 23, 2022). The act defined "covered individuals" to include both current and former U.S. government employees and their family members, as well as current and former members of the Armed Forces and their family members.

government employees and their family members to the Military Health System (MHS).<sup>3</sup> The SECDES application paperwork (package) originates from the component or agency that employs the covered individual.<sup>4</sup> Section 732(d) of the FY 2022 NDAA, as amended, also requires DOD to modify its trauma registry to include certain information on those covered individuals assessed or treated by DOD.

While DOD has extended medical care to non-military employees and family members impacted by AHIs, stakeholders have raised concerns that these patients may face challenges accessing timely care at MTFs. Notably, in March 2023, the DOD Inspector General issued a report finding that SECDES package approvals were prone to delays.<sup>5</sup> Additionally, a Senate committee report accompanying the FY 2023 NDAA included a provision for GAO to review DOD's compliance with Section 732 of the FY 2022 NDAA.<sup>6</sup>

This report examines (1) the challenges AHI patients have faced accessing care in the MHS, (2) how DOD is facilitating AHI patients' access to the MHS, and (3) the extent to which DOD has developed a registry to facilitate AHI research.

To address our first objective, we interviewed 65 AHI patients from various federal entities on their experiences accessing the MHS. To solicit volunteers to be interviewed, we worked with DOD staff to distribute outreach messages through informal AHI patient networks. These messages explained the purpose of our review and provided both classified and unclassified means for patients to contact and be interviewed by the GAO team. We conducted these interviews both in-person and virtually in classified and unclassified venues. All 65 patients voluntarily contacted GAO to share their experiences. As such, their experiences and observations cannot be generalized to the broader AHI patient population. Furthermore, we did not evaluate the AHI reporting and referral processes of specific DOD components or other federal agencies as part of this review. However, we do include general findings on AHI patients' experiences with these processes to provide greater context for understanding the challenges faced by AHI patients prior to entering the MHS.

To address our second and third objectives, we analyzed DOD planning, policy, and guidance documentation, to include DOD's Plan of Action and Milestones (Plan) for facilitating AHI care. We also interviewed relevant DOD officials to discuss efforts underway to implement the Plan, the extent to which they addressed existing patient concerns, and the status of the AHI Registry. For a more detailed description of our scope and methodology, see appendix I.

We conducted this performance audit from February 2023 to June 2024 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our

<sup>&</sup>lt;sup>3</sup>DOD began using a new process for providing MHS access to non-military AHI patients in April 2024. We focus on the SECDES process in our report as it was the process for non-military AHI patients to access the MHS from June 2020 to April 2024.

<sup>&</sup>lt;sup>4</sup>Active-duty service members and their dependents, medically eligible National Guard and Reserve members and their dependents, and retirees and their dependents and survivors affected by AHIs can access the MHS through TRICARE, DOD's regionally structured health care program.

<sup>&</sup>lt;sup>5</sup>Office of the Inspector General, U.S. Department of Defense. *Evaluation of the DOD's Response to Anomalous Health Incidents, or "Havana Syndrome."* DODIG-2023-054 (March 9, 2023).

<sup>&</sup>lt;sup>6</sup>S. Rep. No. 117-130, at 180-81 (2022).

audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

## Background

#### **Anomalous Health Incidents**

In 2016, U.S. Embassy personnel in Havana, Cuba, began to report having an unusual set of symptoms. For some of these patients, their cases began with the sudden onset of a loud noise perceived to be coming from a certain direction and accompanied by pain in one or both ears or across a broad region of the head, and in some cases, a sensation of head pressure, vibration, or dizziness, followed in some instances by tinnitus, visual problems, vertigo, and cognitive difficulties. Initially called Havana Syndrome by the media, the U.S. government labeled them anomalous health incidents when individuals began reporting such events in other countries. AHIs have been reported in several countries, including Austria, China, Colombia, Georgia, Germany, India, Poland, Russia, and Vietnam. Multiple incidents have also been reported within the continental United States. Reported incidents have occurred in employees' workplaces and residences, and during their commutes.

While the reported signs and symptoms of AHIs vary, in some cases, their severity and duration have been intense, leading to lasting cognitive and vestibular (sensory and balance) problems. Affected individuals have included federal employees of the intelligence community and various federal agencies, as well as their family members, including children. Official estimates of those affected by AHIs vary, but as of January 2024, 334 people had qualified for AHI care in the Military Health System. This total included active-duty military, current and former federal employees under SECDES, and their family members.

#### Studies on AHI

Various government agencies and medical researchers have conducted studies on aspects of AHIs, but none have isolated a cause. A March 2023 Intelligence Community Assessment reported that most intelligence community agencies had concluded it was "very unlikely" a foreign adversary was responsible for the reported AHIs, although confidence levels varied. Most of the intelligence community agencies involved assessed that deliberate causal mechanisms were very unlikely to have produced the sensory phenomena and adverse symptoms associated with AHIs, although confidence levels again varied. The assessment also cited critiques of early medical research on AHIs, and pointed to a lack of a consistent set of physical injuries present in AHI cases. The intelligence community agencies assessed that symptoms reported by U.S. personnel were probably the result of factors that did not involve a foreign adversary, such as preexisting conditions, conventional illnesses, and environmental factors. However, the assessment noted that new information would prompt a reassessment. Such information could include an analysis that identified a syndrome linked to

affected personnel. It could also include identification of a specific device that both caused the harmful effects described in AHI reports and was fielded by an adversary during the timeframe of the incidents.<sup>7</sup>

An intelligence community experts panel came to different conclusions in their findings, declassified in February 2022. Specifically, the panel found that known medical and environmental conditions, including psychosocial factors, could not explain some AHI cases with abrupt-onset, location-dependent, audiovestibular phenomena. It concluded that various forms of pulsed radiofrequency energy, as well as focused ultrasound in close-access scenarios, were plausible explanations for these cases, though information gaps existed. It also noted that while psychosocial factors alone cannot account for the core characteristics of AHIs, psychosocial factors may compound some of the incidents with core characteristics.<sup>8</sup> Other incidents reported could be due to hypervigilance and normal human reactions to stress and ambiguity, particularly among a workforce attuned to its surroundings and trained to think about security. The panel did not address the question of attribution to an actor, including the question of whether a foreign actor may be involved.<sup>9</sup>

A number of institutions, including the Centers for Disease Control, National Academies of Sciences, and National Institutes of Health, among others, have conducted medical research on AHIs.<sup>10</sup> However, researchers have noted that such studies face challenges from the lack of a precise AHI case definition; incomplete incident information; a highly diverse population in terms of clinical symptoms and timing from incident to assessment; as well as the classified nature of the affected individuals' circumstances and their work.

### Legislation Granting Access to Military Treatment Facilities

Section 732 of the FY 2022 NDAA required DOD to provide treatment to current government employees and their family members diagnosed with AHI conditions or related afflictions, subject to space availability, at specified locations, including the NICoE or an appropriate MTF. Section 1044 of the FY 2023 NDAA amended section 732, expanding eligibility to "covered individuals" defined to include both current and former U.S. government employees and their family members. AHI patients approved for care through SECDES are seen on a space-available basis. A space-available appointment means an available appointment that would otherwise go unfilled. According to DOD guidance, space-available status places patients at the lowest appointment priority—behind active-duty military (the primary intended beneficiaries of the MHS), retirees, and their family members.

<sup>&</sup>lt;sup>7</sup>Office of the Director of National Intelligence of the National Intelligence Council, *Updated Assessment of Anomalous Health Incidents*, ICA 2023-02286-B (March 1, 2023).

<sup>&</sup>lt;sup>8</sup>Psychosocial factors are social, cultural, and environmental phenomena and influences that affect a person's mental health and behavior.

<sup>&</sup>lt;sup>9</sup>Office of the Director of National Intelligence of the National Intelligence Council, *Complementary Efforts on Anomalous Health Incidents*, Executive Summary of the Experts Panel (declassified February 1, 2022).

<sup>&</sup>lt;sup>10</sup>See for example, Centers for Disease Control and Prevention, *Cuba Unexplained Events Investigation-Final Report* (December 3, 2019); Pierpaoli C., Nayak A., Hafiz R., et al., "Neuroimaging Findings in US Government Personnel and Their Family Members Involved in Anomalous Health Incidents," *The Journal of the American Medical Association* (2024); and Relman D.A., Pavlin J.A., eds; National Academies of Sciences, Engineering, and Medicine; *An Assessment of Illness in U.S. Government Employees and Their Families at Overseas Embassies* (The National Academies Press, 2020).

Section 732 of the FY 2022 NDAA, as amended, also requires the Secretary of Defense to modify DOD's Trauma Registry to include data on the demographics, condition-producing event, diagnosis and treatment, and outcomes of AHIs experienced by covered individuals who were assessed or treated by DOD. DOD's Trauma Registry is a database that captures trauma data from the time service members are injured on the battlefield to when they are treated by providers in the United States. The legislation requires DOD to obtain consent from the covered individual and, if applicable, an agreement from the employing agency for inclusion of this data in the registry.

Additionally, in October 2021, the Helping American Victims Afflicted by Neurological Attacks Act of 2021 (HAVANA Act) became law.<sup>11</sup> This law authorized the Central Intelligence Agency, the Department of State, and other agencies to provide payments to agency personnel who incur qualifying injuries.

#### DOD Entities Associated with AHI Health Care

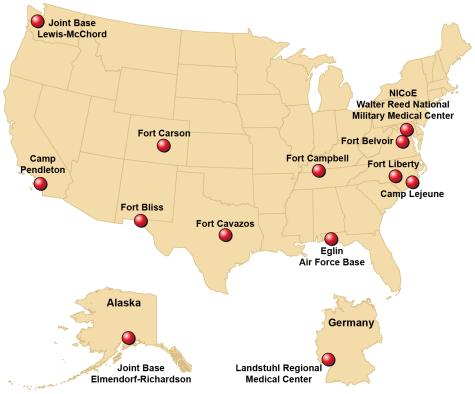
Section 910 of the FY 2022 NDAA directed the Secretary of Defense to establish a cross-functional team (CFT) to address national security challenges posed by AHIs and to ensure that individuals affected by AHI receive timely and comprehensive health care and treatment.<sup>12</sup> In February 2022, the Secretary of Defense designated the Under Secretary of Defense for Policy to lead the CFT that would coordinate the department's AHI response.

AHI patients approved for care in the MHS have their care coordinated by the NICoE. The NICoE in Bethesda is the headquarters of the Defense Intrepid Network for Traumatic Brain Injury and Brain Health. In addition to the NICoE, the Defense Intrepid Network includes 10 Intrepid Spirit Centers inside and two Traumatic Brain Injury and Brain Health Clinics outside the continental United States (see fig. 1).

<sup>&</sup>lt;sup>11</sup>Pub. L. No. 117-46, 135 Stat. 391, 391-96 (Oct. 8, 2021).

<sup>&</sup>lt;sup>12</sup>Pub. L. No. 117-81, Div. A, Title IX, § 910, as amended by Pub. L. No. 117-263, Div. A, Title X, § 1044(a). This section provides that this care and treatment be provided pursuant to title 10, United States Code, for symptoms consistent with an anomalous health incident.

Figure 1: Defense Intrepid Network for Traumatic Brain Injury and Brain Health Locations



Location of Defense Intrepid Network for Traumatic Brain Injury and Brain Health facility

Legend: NICoE = National Intrepid Center of Excellence.

Source: GAO (presentation); health.mil (data); Map Resources (maps). | GAO-24-106593

#### Accessible Text for Figure 1: Defense Intrepid Network for Traumatic Brain Injury and Brain Health Locations

- NICoE = National Intrepid Center of Excellence, Walter Reed National Medical Military Center, Maryland
- 2. Camp Lejeune, North Carolina
- 3. Fort Belvoir, Virginia
- 4. Fort Campbell, Kentucky
- 5. Joint Base Lewis-McChord, Washington
- 6. Camp Pendleton, California
- 7. Fort Bliss, Texas
- 8. Fort Carson, Colorado
- 9. Eglin Air Force Base, Florida
- 10. Fort Liberty, North Carolina
- 11. Fort Cavazos, Texas
- 12. Joint Base Elmendorf-Richardson, Alaska

#### 13. Landstuhl Regional Medical Center, Germany

Source: GAO (presentation); health.mil (data); Map Resources (maps). I GAO-24-106593

In November 2022, DOD completed its multiyear transition of MTFs from the military departments—the Army, the Navy, and the Air Force—to the Defense Health Agency (DHA). This transition placed DHA in charge of overseeing the management and administration of care at over 100 MTFs in the United States, including the NICoE. DHA oversees health care delivery, but the Secretaries of each military department ensure medical readiness with DHA and provide military personnel and other authorized resources to support DHA activities. As of 2022, the MHS offered health care benefits and services to approximately 9.5 million beneficiaries composed of servicemembers, military retirees, and family members.

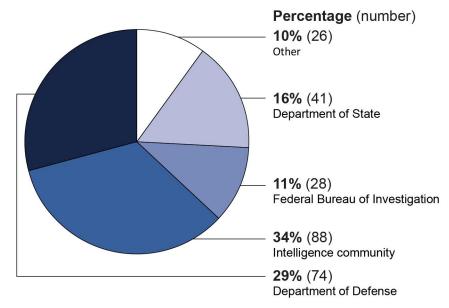
#### <u>Secretarial Designee Process Delays</u>

SECDES is a process by which non-military individuals, including U.S. government employees and their family members can access care through the MHS.<sup>13</sup> DOD used the SECDES process to authorize AHI care for covered individuals through the MHS. AHI patients entering the MHS through SECDES are provided space-available appointments and treatment on a non-reimbursable basis, or free of charge. The SECDES application package originates from the component or agency that employs the covered individual. As of April 2024, 257 individuals (including current and former government employees and their family members) had received SECDES status for treatment of AHIs within the MHS (see fig. 2).<sup>14</sup>

<sup>&</sup>lt;sup>13</sup>The process and eligibility requirements for this program are found in DoD Instruction 6025.23: *Health Care Eligibility Under the Secretarial Designee (SECDES) Program and Related Special Authorities* (Sept. 16, 2011) (incorporating change 2, May 28, 2020).

<sup>&</sup>lt;sup>14</sup>We obtained data from the Department of Defense on processing times for Secretarial Designee (SECDES) packages from June 2020 to April 2024. To assess the reliability of these data, we interviewed DOD officials, conducted standard outlier tests, and analyzed the variables for clear errors or missing data. We determined, based on these steps, that the data were sufficiently reliable for the purposes of our reporting objectives.

Figure 2: Anomalous Health Incident Secretarial Designees by Agency as of April 2024



Source: GAO analysis of Department of Defense data. | GAO-24-106593

#### Accessible Data for Figure 2: Anomalous Health Incident Secretarial Designees by Agency as of April 2024

	Percentage	Number
Other	10	26
Department of State	16	41
Federal Bureau of Investigation	11	28
Intelligence community	34	88
Department of Defense	29	74

Source: GAO analysis of Department of Defense data. I GAO-24-106593

Note: In this report, we define Intelligence community as employees of the Central Intelligence Agency and the Office of the Director of National Intelligence. Our Department of Defense category includes employees of defense intelligence agencies, such as the Defense Intelligence Agency, the National Security Agency, and the National Geospatial-Intelligence Agency, as well as civilian employees from the military services. The Other category includes employees of the Departments of Homeland Security and of Agriculture, the National Security Council, and the United States Agency for International Development.

In March 2023, the DOD Inspector General issued a report finding that SECDES package approvals were prone to delays.<sup>15</sup> In response, DOD committed to a 14-calendar day target for processing SECDES packages and formalized its procedures for meeting this deadline in September 2023 (see fig. 3).<sup>16</sup>

<sup>&</sup>lt;sup>15</sup>DODIG-2023-054 (March 9, 2023).

<sup>&</sup>lt;sup>16</sup>DOD committed to a processing target of 14 calendar days in response to the DOD-IG report. However, when DOD finalized standard operating procedures, it used 10 business days as its target. According to DOD officials, 14 calendar days and 10 business are interchangeable as the 10 business days account for 4 non-working calendar days, or weekends, over the course of 2 weeks.

Figure 3: Intended Secretarial Designee Approval Timeline for Anomalous Health Incident Patients

Number of
business
days

#### **Phase**



#### Phase 1 (1-2 business days)

- 1. Sponsoring Agency Sends Request for Care to Office of the Assistant Secretary of Defense for Health Affairs (OASD(HA)).
- The Director, Coalition and Non-Beneficiary Health Care (CNBHCP), sends the request to National Intrepid
  Center of Excellence and enters the request into the Correspondence and Task Management System. The
  Director then notifies Health Affairs-Correspondence Control Office (HA-CCO) that the Secretarial Designee
  (SECDES) package is ready for coordination.



#### Phase 2 (6 business days)

- HA-CCO coordinates the SECDES package. HA-CCO simultaneously coordinates sections of the SECDES package with the Joint Staff Surgeon, Office of General Counsel, and the Comptroller.
- 2A. Option 1: If no comments arise, then HA-CCO sends the SECDES package to the HA front office for final approval.
- 2B. Option 2: If comments arise, the CNBHCP resolves questions and comments, and then sends reworked packages back to HA-CCO for resubmission to the Joint Staff Surgeon, Office of General Counsel, and the Comptroller. If no new comments arise, HA-CCO sends the SECDES package to the HA front office for final approval.



7

8

#### Phase 3 (1-2 business days)

- OASD (HA) sends the package to the Undersecretary of Defense for Personnel and Readiness for final review and signature.
- 2. HA-CCO uploads the signed package into the Correspondence and Task Management System and sends a copy to the Director, CNBHCP.
- 3. The Director, CNBHCP, sends the signed Approval Memo to the sponsoring agency, National Intrepid Center of Excellence, and the Cross-Functional Team.
- 4. The sponsoring agency distributes the approval memo to the patient.

Source: GAO analysis of Department of Defense documents; GAO (icon). | GAO-24-106593

However, since DOD formalized its processing target, only 17 percent of SECDES packages have met the target of 14 calendar days. We show the average time to process SECDES packages in table 1.

Table 1: Department of Defense Secretarial Designee Processing Times by Calendar Year

Year <sup>a</sup>	Mean Processing Time (in calendar days)	Number of Requests	Percentage of Packages Processed in 14 calendar days or less <sup>b</sup>
2020	25	5	20%
2021	20	141	28%
2022	54	68	4%
2023	22	36	31%
2024	19	7	14%
Mean, Number, and Percentage <sup>c</sup>	29	257	22%

Source: GAO analysis of Department of Defense (DOD) data. | GAO-24-106593

Notes: The data shown are Secretarial Designee processing times for anomalous health incident patients. The 2024 data are as of April 1, 2024. The Secretarial Designee processing window begins when the Office of the Assistant Secretary of Defense for Health Affairs receives the Inter-Agency Request for care. The processing window closes when the Undersecretary of Defense for Personnel and Readiness signs the completed Secretarial Designee package.

GAO has not independently reviewed the Secretarial Designee paperwork to confirm the processing times. The data above are only for new requests for Secretarial Designee status. Requests for Secretarial Designee status renewal are not included.

According to DOD officials, the number of offices and the level of authority required to coordinate and approve SECDES packages complicated efforts to reliably meet the target of 14 calendar days. Packages must be approved by the Undersecretary of Defense for Personnel and Readiness and reviewed by DOD's Office of General Counsel, Office of the Joint Staff Surgeon, and Office of the Secretary of Defense Comptroller. Furthermore, the pace of SECDES approvals has varied. For example, in the 12 months from July 2020 to July 2021, DOD approved 46 patients for SECDES status, but in the 5 months from August to December 2021, it approved 100 patients for SECDES status. According to DOD officials, such surges made it difficult to maintain the pace of onboarding. We show SECDES package approvals by month in figure 4.

Figure 4: Secretarial Designee Package Approvals by Month

Number

30

25

20

Jul Aug Sep Oct Nov Dec Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec Jan Feb Mar Apr May Jun

Source: GAO analysis of Department of Defense data. | GAO-24-106593

-	Accessible Data for	r Figure 4: Secretarial De	signee Package Approvals by Month
	Year	Month	Number

Year	Month	Number
2020	Jul	1
2020	Aug	0
2020	Sep	0
2020	Oct	0
2020	Nov	1
2020	Dec	0
2021	Jan	3
2021	Feb	1
2021	Mar	8

<sup>&</sup>lt;sup>a</sup>The year a request for Secretarial Designee status began processing.

<sup>&</sup>lt;sup>b</sup>DOD formalized its procedures for meeting its 14-calendar day deadline in September 2023.

<sup>&</sup>lt;sup>c</sup>Mean is weighted by the number of requests by year.

Year	Month	Number	
2021	Apr	4	
2021	May	5	
2021	Jun	14	
2021	Jul	9	
2021	Aug	17	
2021	Sep	25	
2021	Oct	14	
2021	Nov	30	
2021	Dec	14	
2022	Jan	0	
2022	Feb	3	
2022	Mar	3	
2022	Apr	4	
2022	May	0	
2022	Jun	17	
2022	Jul	0	
2022	Aug	1	
2022	Sep	2	
2022	Oct	1	
2022	Nov	6	
2022	Dec	3	
2023	Jan	8	
2023	Feb	24	
2023	Mar	1	
2023	Apr	7	
2023	May	1	
2023	Jun	3	
2023	Jul	6	
2023	Aug	6	
2023	Sep	3	
2023	Oct	1	
2023	Nov	2	
2023	Dec	1	
2024	Jan	2	
2024	Feb	4	
2024	Mar	2	

Source: GAO analysis of Department of Defense data. I GAO-24-106593

Notes: The data shown are Secretarial Designee approvals for anomalous health incident patients. The first approvals were in July 2020. The 2024 data are as of April 1, 2024.

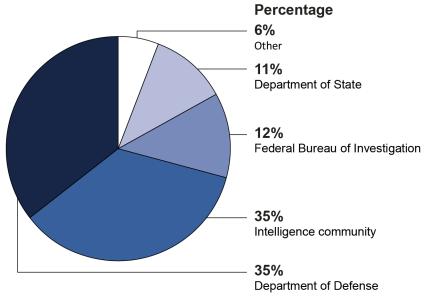
A package is considered approved when the Undersecretary of Defense for Personnel and Readiness signs the package. Some packages may have begun processing in one calendar year but were not approved until the next calendar year. Therefore, some calendar years may have more approvals than requests for care.

The data above are only for new requests for Secretarial Designee status. Requests for Secretarial Designee status renewal are not included.

# AHI Patients Face Several Challenges Accessing Care in the Military Health System

We identified several challenges to accessing AHI care in the MHS in the interviews we conducted with 65 AHI patients associated with 14 federal entities (see fig. 5).<sup>17</sup>

Figure 5: Agency Breakdown of Anomalous Health Incident Patients Interviewed by GAO



Source: GAO. | GAO-24-106593

#### Accessible Data for Figure 5: Agency Breakdown of Anomalous Health Incident Patients Interviewed by GAO

	Percentage	
Other	6	
Department of State	11	
Federal Bureau of Investigation	12	
Intelligence community	35	
Department of Defense	35	

Source: GAO. I GAO-24-106593

Note: In this report, we define Intelligence community as employees of the Central Intelligence Agency and the Office of the Director of National Intelligence. Our Department of Defense category includes employees of defense intelligence agencies, such as the Defense Intelligence Agency, the

<sup>&</sup>lt;sup>17</sup>Our interview cohort comprised 27 men and 38 women, 43 of whom had experienced their first AHI in 2019 or later. Twenty-six people experienced their AHI domestically, 35 people overseas, two people experienced AHIs in both domestic and overseas locations, and two people were unable to disclose or pinpoint a location. At the time of our interviews, 55 of these patients had obtained access to the MHS and 50 had begun receiving care. Of these 50, 28 patients primarily used the NICoE at Walter Reed, six people primarily used Fort Belvoir, 10 people primarily used other Defense Intrepid Network locations, while six reported using a combination of MHS facilities.

National Security Agency, and the National Geospatial-Intelligence Agency, in addition to civilian employees from the military services. Other includes employees of the Department of Homeland Security, the National Security Council, the United States Agency for International Development, and the United States Department of Agriculture. The agency categories were created using data from the entire population of AHI patients with secretarial designation and are not meant to imply that GAO spoke to an employee from every agency listed for a category.

Overall, patients reported inconsistent support from their home agencies before seeking MHS treatment, limited information upon entering the MHS, and difficulty scheduling appointments when using the MHS. Furthermore, the lack of an official DOD mechanism to communicate authoritative information led AHI patients to develop informal support networks that did not always communicate reliable information.

## Inconsistent Agency Support and Other Issues Present Challenges to AHI Patients before They Enter the Military Health System

#### Patients Described Being Stigmatized by Their Employing Agency after Reporting their Anomalous Health Incidents (AHI)

Thirty one out of the 65 patients we spoke to described being stigmatized by their employer after reporting their AHI, which led to negative effects on their career. Some patients were pulled from their work assignments. Others discussed being referred to see psychologists after reporting or having delayed renewals of their security clearances. In some cases, patients reported being placed on leave or losing their jobs, which patients attributed to coming forward with their AHI incidents. Several patients stated they chose not to disclose their AHI events to supervisors or colleagues as they were concerned it would have a negative effect on their career.

The patients reporting stigmatization attributed these experiences to their agencies not believing them. Several patients reported their agencies sent messaging that suggested AHIs were not real or that symptoms could be explained by other factors. Some patients faced disbelief from their supervisors after disclosing their AHI incident, while others attended meetings where agency leadership cast doubt on those reporting. Some patients discussed being made to feel "crazy" by their agency medical teams after reporting their AHI incidents, as agency medical staff cast doubt on their experiences.

Source: GAO patient interviews. | GAO-24-106593

AHI patients we spoke with cited a series of challenges they faced before ever entering treatment in the MHS.<sup>18</sup> These challenges generally encompassed inconsistent support from their home agencies and other difficulties accessing treatment in the private medical sector. Patients reported that their home agencies were unhelpful, slow, or unclear on how to apply for SECDES status, in some cases delaying access to medical treatment in the MHS.

<sup>&</sup>lt;sup>18</sup>This section contains general findings on AHI patients' experiences prior to entering the MHS. We did not evaluate the AHI reporting and referral processes of specific DOD components or other federal agencies as part of this review. However, we include these patient experiences here to provide greater context for understanding the challenges faced by AHI patients.

Thirteen patients stated that their home agencies never informed them that accessing the MHS through SECDES was an option, learning of it instead through informal AHI support networks. Twelve patients reported delays in their SECDES status due to slowness on the part of their home agency. In six cases, agencies did not inform patients that DOD had approved their MHS access until they specifically inquired. These delays in communication ranged from 3 weeks to over a year.

Some patients attributed these problems to new and evolving agency processes and policies for responding to AHI events. Others believed their agencies did not take their AHI reports seriously (see sidebar for more information.) At least five AHI patients we spoke to had positive experiences with their home agencies. For example, these patients discussed their agency taking their AHI report seriously, and others discussed their agency moving quickly to secure them SECDES status after they reported their incident.

Patients also relayed challenges securing treatment in the civilian medical sector before entering the MHS. Eighteen patients noted that it was difficult to find doctors who were aware of AHIs or Havana Syndrome, particularly outside of the Washington, D.C. area. This situation made it harder to find effective medical treatment domestically and was further complicated for patients and their families stationed at overseas posts. Additionally, patients from the intelligence community and other agencies were often unable to fully share the circumstances of their condition with civilian medical providers. In many cases, these patients withheld information from their caregivers either because they never received guidance from their agencies on how to talk about their AHIs with uncleared civilian doctors or their agencies had told them not to share any information about their incidents. This inability to discuss potential causes made it more difficult for some AHI patients to access effective medical care.

#### Patients Reported Inconsistent Agency Support while Pursuing Worker's Compensation or HAVANA Act Payments.

The Federal Employees' Compensation Act (FECA) authorizes compensation and other benefits to federal employees who have sustained work-related injuries or illnesses by providing monetary and medical benefits. Department of Labor processes anomalous health incident (AHI) patients' claims under FECA for their AHI injuries.

FECA applications go to Department of Labor for a factual and medical review. If the employing agency agrees an AHI occurred within the performance of duty, Department of Labor accepts the AHI incident as factual and proceeds with a review of the medical evidence of record. Some patients reported their agencies refused to concur that their AHI was a result of their work, which led to their applications being denied or delayed. Others reported that their agencies supported them through the application process with additional documentation or guidance on how to apply.

AHI patients can also apply for payment from their agency for a qualifying injury to the brain under the Helping American Victims Afflicted by Neurological Attacks Act of 2021 (HAVANA Act). Some patients reported their agencies had not yet implemented rules for the HAVANA Act, which prevented them from applying. Others reported little to no guidance on how to apply, while others reported they had no idea the program existed.

Of the 65 patients we spoke to, two reported receiving HAVANA Act payments while nine reported receiving worker's compensation. Twelve people were actively pursuing one or both payments.

Source: GAO patient interviews. | GAO-24-106593

Several patients who sought medical treatment in the civilian sector reported incurring significant medical expenses. Such expenses were particularly true for those that sought specialized or experimental treatments for AHI symptoms. A minority of patients we spoke with (11 of 65) told us they had successfully qualified for HAVANA Act payments or worker's compensation (see sidebar).

## AHI Patients Received Limited Onboarding and Care Information When Entering the Military Health System

According to CFT officials, patients seeking AHI care through SECDES status typically have no prior experience with the MHS and require greater communication and guidance to effectively navigate the system. Many of the 50 patients we spoke to who had started treatment in the MHS were grateful for the care they had received. Twenty-three patients reported symptom improvement because of their time in the MHS, and 25 patients appreciated having access to providers who were knowledgeable about AHIs.

However, the patients we spoke to also noted they had received limited information from DOD on how to navigate the MHS and what care options were available to them. Thirty-four patients lacked some form of initial onboarding information. For example, 15 patients reported they did not receive any overview, written or oral, on basic information about their assigned medical facility, such as who to contact or what resources (such as parking) were available. Another 10 patients encountered difficulties getting onto the military base where their facility was located, either because patients did not know what documentation they needed, or because of other badging issues. Ten patients also reported difficulty obtaining their prescriptions at MHS pharmacies, often because they were unaware of local pharmacy procedures or because local pharmacy systems did not recognize their SECDES status. In some cases, these difficulties led to patients' prescriptions lapsing. Twenty patients we interviewed could not easily access their medical records, which prevented some of their MHS doctors from seeing tests conducted by outside (non-MHS) providers. Patients also noted that MHS records would not always easily transfer to their non-MHS providers.

Patients also lacked consistent information on how space-available status affected their care. A space-available appointment means an available appointment that would otherwise go unfilled. This status places space-available patients at a lower appointment priority than active-duty military (the primary intended beneficiaries of the MHS), retirees, and their family members. DOD officials explained rules vary at different clinics, but appointment calendars are generally not available for space-available scheduling until closer to the actual appointment date. Thus, space-available patients may have fewer appointments to choose from and no guarantee that any will be available. As a result, space-available patients may face longer wait times before they can see medical personnel. Additionally, the shorter notice with which the MHS offers these appointments can prevent long-term scheduling. According to DOD officials, this dynamic can be further complicated when scheduling referrals at separate clinics for specialized medical care; for example, it may be difficult or impossible to schedule appointments in multiple clinics on the same day.

DOD officials asserted that the NICoE does have, and continues to have, capacity to bring civilian AHI patients in at the same speed and access to care measures that active-duty patients have. While they acknowledged some challenges for specialty care, they stated that the majority of AHI patients entered specialty care quickly and with the same access as active-duty patients. However, NICoE officials acknowledged they did not issue guidance to AHI patients explaining space-available care.

AHI patients also received conflicting information on what durable medical equipment—equipment and supplies provided for everyday or extended use—they could receive through the MHS under space-available status. For example, while the initial SECDES letters specifically referenced the provision of durable medical equipment, they did not explain what that meant under space-available care. Later SECDES letters did not mention durable medical equipment at all.

AHI patients entering the MHS through SECDES are provided space-available appointments and treatment on a non-reimbursable basis, or free of charge, but that is not always the case for durable medical equipment. According to DOD officials, under space-available care, AHI patients can receive durable medical equipment that is already available "off the shelf" at their assigned medical facility, such as crutches. Durable medical equipment not immediately available that has to be ordered from offsite is not covered by DOD and must be paid for by the patient's private insurance. For example, several patients we spoke with received prescriptions for eyeglasses they could not obtain from DOD.

However, according to DOD officials, DOD has inconsistently applied this coverage over time due to confusion over what constituted "off the shelf" durable medical equipment for SECDES patients. For example, some military health facilities have larger stocks of durable medical equipment on site (such as eyeglasses and hearing aids) than others. As a result, some AHI patients had their durable medical equipment covered by DOD, while others did not. Among the 50 AHI patients who had begun treatment within the MHS, 15 stated they were specifically denied equipment, such as continuous positive airway pressure (CPAP) machines, 19 hearing aids, eyeglasses, or contacts. However, another 21 did obtain hearing aids, eyeglasses, or contacts through DOD at no cost.20

According to DOD officials and patients, private insurance does not always cover CPAPs and hearing aids, and these items sometimes require significant out of pocket payments from patients. Thus, seeing other AHI patients receive these items free of charge from DOD can fuel perceptions of inequity.

Finally, AHI patients we spoke with often had limited information about their care options within the MHS. Of the 50 patients who had begun treatment within the MHS, 21 did not receive information on what their care process would entail or what treatment options might be available. Some of those 21 patients reported not knowing why they were going to certain appointments or treatments. Others reported they only learned about certain care options available to them through talking to other AHI patients. Another 15 patients stated they did not discuss or receive a plan regarding long-term care while in the MHS. Some of these 15 patients reported being uncertain on how long they could stay in the MHS. Others knew they had indefinite access rights to the MHS but were uncertain of what long-term care would entail in terms of available appointments and treatments.

NICoE officials acknowledged that they do not provide written documentation or guidance to AHI patients during their initial outreach. Instead, case managers or care providers often communicate such information orally. However, other DOD officials noted that AHI patients experiencing cognitive decline may not effectively retain information communicated orally and have recommended the development of written guidance to provide essential MHS information. DOD plans to develop a patient handbook that will explain AHI entitlements to patients but has not determined a timeframe for its implementation.

<sup>&</sup>lt;sup>19</sup>A CPAP is a machine that uses mild air pressure to keep breathing airways open while a patient sleeps.

<sup>&</sup>lt;sup>20</sup>As of February 2024, NICoE's policy is for providers to write a prescription for SECDES AHI patients to obtain any prescription eyeglasses, CPAP machines, or hearing aids outside the MHS using their own insurance. For AHI patients already issued hearing aids by the MHS prior to February 15, 2023, the MHS will continue to provide an annual audiogram and provide hearing aid repairs, as needed, through the end of the warranty.

Federal internal control standards state that management should select appropriate methods to communicate quality information to external stakeholders to achieve an entity's objectives.<sup>21</sup> Because of the lack of formal, written guidance, AHI patients under SECDES navigate the MHS with varying levels of knowledge, which leads to inconsistent care experiences that could worsen health outcomes as some patients access treatments that others do not.

### Problems Scheduling Appointments Complicated Patients' Access to Care

#### The Majority of Patients We Interviewed Cited Scheduling Difficulties

Of the 50 AHI patients we spoke with who had begun treatment within the MHS, 36 patients cited scheduling difficulties as a challenge to accessing care, and 20 patients believed that scheduling difficulties had grown worse over time. For example, some patients noted that NICoE staff would initially help schedule appointments with non-NICoE providers within the MHS, such as the Pain Management Clinic at Walter Reed. Over time, however, these patients noted they had to make more appointments on their own. If trying to secure an appointment outside the NICoE, they would often have to explain to non-NICoE staff how to look them up in the system as a SECDES patient, which caused delays for patients seeking care.

Of the 36 patients reporting scheduling problems, many noted the lack of a reliable point of contact, citing frequent turnover among their assigned schedulers. Patients reported NICoE now has a group inbox to email and a phone line to call, but noted it is difficult to get responses. For example, some patients reported they waited months to secure an initial appointment with a doctor. Other patients who had been receiving consistent appointments at the NICoE noted communication seemed to drop off, and they suddenly found it very difficult to schedule additional appointments. Some patients stated they had waited so long for a response from the NICoE that they had essentially given up on the MHS and were pursuing treatment in the civilian sector. These scheduling

<sup>&</sup>lt;sup>21</sup>GAO, Standards for Internal Control in the Federal Government, GAO-14-704G (Washington, D.C.: September 2014).

#### Parents Reported Challenges to Accessing Pediatric Anomalous Health Incident (AHI) Care in the Military Health System (MHS)

Department of Defense officials estimated that about 15 children had received Secretarial Designation for AHIs as of December 2023. Parents we spoke to reported a variety of challenges accessing pediatric care for their AHI-affected children. Parents shared that they did not have a clear point of contact to work with in the pediatric unit. All the parents we spoke to were themselves receiving treatment for an AHI. In some cases, parents reported National Intrepid Center of Excellence (NICoE) care managers stepped in to assist with scheduling pediatric appointments, but noted these care managers would not always work with them to coordinate their appointments with their children's appointments. Parents also reported it would take a long time to secure appointments and to schedule recommended follow-ups. Parents noted these challenges limited the usefulness of the pediatric AHI care offered within the MHS

According to officials, the NICoE primarily serves adults, and it has no pediatricians on staff. Walter Reed has pediatricians, but officials noted a limited number of pediatric appointments, particularly for specialists.

Source: GAO patient interviews. | GAO-24-106593

issues were also reported by parents seeking pediatric services for children affected by AHIs (see sidebar for more information.)

CFT and DHA officials acknowledged scheduling is a problem for AHI patients. According to these officials, NICoE generally has space available for patients, but other care services at Walter Reed, such as the pain clinic and neurology services, do not. As a result, when AHI patients are referred to these services, they often experience long waits because they are scheduled for these appointments after active-duty, retired service members, and their family members. Moreover, securing referral appointments under space-available can be complicated, according to CFT officials. Some clinics within the MHS will schedule referral appointments if the patient calls them directly, but for others, the patient must call a special referral number. CFT officials confirmed that when AHI patients call the clinics or the referral numbers, staff sometimes does not know what SECDES status is, which can delay scheduling for AHI patients.

### Officials Attributed Scheduling Weaknesses Partly to Processing Delays and Hiring Struggles

CFT and NICoE officials attributed many of these scheduling weaknesses to paperwork processing delays and difficulties filling positions, among other things. In September 2021, DOD awarded a contract to support the hiring of 11 full-time employees (including case managers and care providers) to support AHI care at the NICoE at Walter Reed, and at the Intrepid Spirt Center at Fort Belvoir, according to DOD documents.<sup>22</sup> However, the first employee hired by the contractor did not start until April 2022. According to DOD officials

<sup>&</sup>lt;sup>22</sup>DOD subsequently added more positions to the contract, and as of February 2024, the contract contained 16 full time equivalent positions between Walter Reed and Fort Belvoir, according to DOD documents.

and a March 2022 contract discrepancy report, the contractor at times submitted paperwork for security and credentialing checks that contained mistakes or missing information, leading to longer processing times for candidates. For example, one candidate had a credentialing package sent in November 2021 but did not start working until June 2022. During the credentialing process, candidates also withdrew from consideration for positions. For example, four people dropped out of consideration for a nurse care manager position during the credentialing process. After the contract discrepancy report was filed, the contractor took several corrective steps, such as holding weekly meetings with DOD to ensure credentialing package quality had improved, holding a training for their credentialing specialists, and having credentialing packages reviewed by a team leader.

NICoE officials noted other factors may have also played a role in delaying the hiring for these positions, such as difficulties in identifying suitable candidates and untimely completion of security paperwork by applicants. NICoE officials also noted that some of the candidates hired by the contractor were poorly trained or underperforming, which led to the contractor dismissing some of them. Further, both NICoE officials and contractor documentation noted that a competitive job market for healthcare workers presented challenges to hiring.

These vacancies hampered DOD's ability to provide timely access to care for AHI patients in several ways. First, DOD had envisioned that the nurse case managers on the contract would handle many aspects of patient administration, including scheduling. However, the first care manager started in June 2022, the contractor was not able to fill more than one care manager position at any given time. After that staff member resigned in June 2023, there were no AHI case managers active on the contract until November 2023. NICoE officials stated that they would divert staff from other patient duties to assist when there were no case managers. However, they noted that diverting staff made it difficult to maintain continuity between patients' case managers as staff frequently rotated or divided duties among each other. DOD officials also explained that since AHI patients are not the primary users of the MHS, scheduling, organizing base access, and performing other administrative tasks for them are more time-consuming than doing so for active-duty military and their family members.

Second, vacancies in medical provider positions increased wait times. According to NICoE officials, DOD had planned to hire two primary care physicians on the contract—one to support the AHI call center by managing referrals and intakes and another to manage face-to-face appointments. Since DOD's contractor hired the first primary care physician in May 2022, NICoE officials noted that there had only been a few weeks when two primary care physicians were on contract. As a result, one primary care physician has been splitting duties between call center support and patient appointments. Besides slowing the pace of patient intake, this staff shortage has reduced available time for administrative duties, such as development of policy and procedure documents, or care process improvement, according to NICoE.

Finally, NICoE officials stated that vacancies have left the NICoE understaffed and unable to adjust when large numbers of AHI patients enter the MHS at the same time. For example, according to DOD data, the number of SECDES approvals increased from five in 2020 to 141 in 2021, with 100 of those occurring in the final 5 months of 2021. During these surges, officials stated that the NICoE must balance continued care of its previous patients with scheduling intake appointments for new patients, which can lead to further delays.

As of February 2024, the contractor had filled nine of 16 positions, including one of three case managers, and one of two primary care providers. According to NICoE, if all four option years are exercised under the current award, this contractor will continue to provide care for AHI patients through September 2026.

## DOD Lacks Official Mechanism to Communicate Authoritative Information with AHI Patients

DOD has no official mechanism for communicating information about AHI medical care in the MHS. This fact has led AHI patients to use the CFT and informal support networks to navigate the MHS, which in turn led to inconsistent care experiences and lessened trust in MHS providers.

### <u>Declining Quality of Official NICoE Communication Led Patients to Use CFT Personnel for Support</u>

As existing communication channels declined, some AHI patients turned to the CFT to navigate the MHS. According to DOD officials, NICoE leadership used to reach out to all AHI patients to discuss their upcoming care. However, as patient volume increased, leadership was no longer able to speak to every AHI patient. As communication from leadership lessened, patients were also experiencing turnover in key NICoE staff positions that provided them information and support, like the nurse case manager position. At least five AHI patients noted the declining quality of communication with NICoE as their case managers left. According to DOD officials, the NICoE did not effectively inform AHI patients about case manager turnover or set up any effective alternate communication channels to inform AHI patients during this time. They noted that for a time, AHI patients were attempting to schedule appointments through the unmonitored email address of a care manager who had since moved on. Likewise, some patients we spoke with were often unclear about whom they should contact to resolve scheduling problems.

Officials from the CFT, NICoE, and DHA noted that the NICoE could do more to set clear expectations for what AHI patients will receive, and how long they can expect to receive it. Of the 50 patients who had begun treatment within the MHS, 21 reported they did not receive information on what their care process would entail, or what treatment options might be available. Furthermore, patients also noted poor communication from NICoE when it denied certain treatments or tests, changed care providers, or discontinued certain therapeutics. These communication weaknesses can lead to problems when patients compare treatment experiences with each other. For example, one NICoE official noted that several early AHI patients went through the NICoE's Intensive Outpatient Program, a 4-week interdisciplinary program for patients diagnosed with traumatic brain injury and associated health conditions. However, this set up a false expectation that all AHI patients would be part of this program, and if they were not, then their care was somehow substandard. Some patients also did not have a clear idea of what their long-term care in the MHS would look like, either because they had incomplete information or had fallen out of contact with the NICoE.

Without clear points of contact or communication from the NICoE, patients turned to officials in the CFT to help them with a variety of problems, such as securing appointments and follow-ups, resolving base access issues and pharmacy delays, and assisting with paperwork for compensation programs like the Federal Employees' Compensation Act. Many patients we spoke to praised CFT staff highly for their dedication to patient advocacy. However, patients unaware of the CFT could not take advantage of it. The CFT's support to patients also sometimes created friction with the NICoE. For example, AHI patients would sometimes ask the CFT to inquire at the NICoE why some patients received more testing than they themselves had received. Some officials believed that this dynamic undermined trust in medical providers. Others stated that effective communication from the NICoE could have prevented the problem in the first place. Finally, this support may no longer be available, as the two CFT staff who were tasked with, and most associated with, patient advocacy have since moved on to other positions.

## AHI Patients Navigate the Military Health System through Informal Networks That May Contain Unreliable Information

Patients and DOD officials reported that AHI patients developed informal support networks to navigate the MHS in the absence of consistent official communication. Sometimes, these networks shared valuable information, such as what treatments were available in the MHS or how to qualify for worker's compensation. However, these informal networks do not always provide the type of accurate information needed for a healthy recovery, according to patients and officials.

First, these informal networks do not always communicate accurate medical information about AHI treatments. Patients and officials noted that because AHI is a new, unknown condition, members of these networks are prone to sharing many theories, not all of which are helpful for patient recovery. Additionally, DOD officials noted that patients in these networks inevitably compare the care they are receiving, and, without expectation-setting from the NICoE about what treatments patients will receive, these comparisons create perceptions of inequitable care and degrade patients' trust in MHS providers.

Second, without an official narrative from the NICoE or DHA to counter misinformation, officials stated that these networks can give rise to unnecessary "fear-spiraling." For example, when the MHS transitioned to a new record system (Genesis) in the Spring 2023, this development temporarily led to reduced appointment availability and increased wait times for all beneficiaries scheduling appointments at the Walter Reed National Military Medical Center and Fort Belvoir Community Hospital. This change coincided with the release of the March 2023 Intelligence Community Assessment, which cast doubt on some aspects of AHIs. According to a CFT official familiar with informal AHI networks, this fact led many AHI patients to believe that NICoE was limiting care due to the conclusions of the March 2023 Intelligence Community Assessment. This official believed that NICoE could have avoided this misconception if it had proactively communicated the upcoming transition to AHI SECDES patients and its potential impact on scheduling in the same way that it was communicated to active-duty patients.

Federal internal control standards state that management should communicate with, and obtain quality information from, external parties using established reporting lines. Until DOD develops a direct source of official communication to AHI patients, these patients may continue to use informal networks where they risk receiving inaccurate medical information, perceiving inequities in medical treatment, and losing trust in MHS providers.

# DOD Plan for Facilitating AHI Care Contains Uncertain Timeframes and Lacks Monitoring Provisions

DHA has developed a Plan that may address some of the patient issues reported to us. For example, DHA's Plan includes a new approval process for AHI patients to enter the MHS and an enhanced AHI Care Coordination Cell to support patients while in the MHS. These initiatives may address some patient challenges, such as slow patient approval and inconsistent support. However, the timeframes for task implementation are uncertain. Moreover, the Plan does not contain components for monitoring these two key tasks, which could undercut its success.

### DOD Plan May Address Some Patient Issues but Its Timeframes are Uncertain

### <u>DOD Has Developed a New Process for Patient Approval and Plans to Enhance Its AHI Care</u> Coordination Cell

In January 2023, the Assistant Secretary of Defense for Health Affairs (ASD(HA)) instructed the Director of DHA to execute seven tasks intended to improve access, care, and clinical guidance for treating AHI patients. In August 2023, ASD(HA) approved DHA's Plan that contained over 100 sub-tasks to accomplish these tasks. DHA's Plan includes a new Section 732 approval process for AHI patients to enter the MHS, as well as an enhanced AHI Care Coordination Cell. The Section 732 approval process aims to streamline review by establishing approval authority at a lower level than the current SECDES process and will completely replace that process for AHI patients.

Specifically, the DHA's Deputy Assistant Director for Medical Affairs is responsible for patient approval instead of the Undersecretary of Defense for Personnel and Readiness. In addition, DHA handles coordination of AHI patient approval documents, rather than relying on review by DOD's Office of General Counsel, Joint Staff Surgeon, and Comptroller. Finally, at the end of the process, DHA communicates MHS access approval directly to the patient, rather than relying on communication by the home agency (see fig. 6). Changing the approval authority, having DHA handle the coordination of patient documents, and communicating approval directly to the patients could potentially address processing and communication problems associated with the SECDES process. The Section 732 approval process became operational in April 2024.

Figure 6: Comparison of Department of Defense's Secretarial Designee Process with Section 732 Approval Process Secretarial Designee **New Section 732** Sponsoring agency sends request for care. (SECDES) process approval process Phase 1 (2 business days) Defense Health Agency (DHA) Operations Center receives Office of the Assistant Secretary of Defense for and reviews the official Request for AHI Provision of Care Health Affairs receives requests for care. and then inputs the request into Enterprise Task Management Software Solution. The Director, Coalition and Non-Beneficiary Health Care (CNBHCP) sends the request to National Intrepid Center DHA Operations notifies the Assistant Director for Health of Excellence (NICoE) and enters the request into the Care Administration, Medical Affairs that Section 732 Correspondence and Task Management System. approval is ready for coordination. The Director, CNBHCP notifies Health Affairs-The Deputy Assistant Director, Medical Affairs, Clinical Correspondence Control Office (HA-CCO) that the Support Division's (DAD-MA/CSD) AHI point of contact SECDES package is ready for coordination. reviews and coordinates request. According to Department of Defense (DOD) officials, DHA Phase 2 (6 business days) managing the coordination process should be faster than the SECDES coordination process. HA-CCO simultaneously coordinates sections of the SECDES package with the Joint Staff Surgeon, Office of General Counsel, and the Comptroller. DAD-MA/CSD AHI point of contact sends request to DAD-MA for review and signature. According to DOD officials, lowering the signing authority for care CNBHCP resolves questions and comments, then HA-CCO to the DAD-MA should accelerate the approval process. sends package to HA front office for approval. Phase 3 (2 business days) After approval is signed by DAD-MA, DAD-MA/CSD AHI point of contact uploads all finalized documents to Enterprise HA front office sends package to Undersecretary of Defense Task Management Software Solution. for Personnel and Readiness for final approval. After package is signed by the Undersecretary of Defense for Personnel and Readiness, HA-CCO uploads the signed DAD-MA/CSD AHI point of contact provides copies to DHA package into Correspondence and Task Management Operations Center, DHA Patient Administration, NICoE care System and sends a copy to the Director, CNBHCP. team, patient, and referring federal agency. DHA plans to communicate approval directly to patients as opposed to the SECDES process where the sponsoring agency The Director, CNBHCP sends the signed Approval Memo communicates the approval. to the sponsoring agency, NICoE, and the AHI Cross-Functional Team. The sponsoring agency distributes the Approval Memo to the patient (not subject to DOD deadline).

Source: GAO analysis of Department of Defense documents. | GAO-24-106593

Note: The Section 732 approval process is how DOD refers to the new process by which the agency is implementing section 732 of the National Defense Authorization Act for Fiscal Year 2022. Pub. L. No. 117-81, 135 Stat. 1541, 1797 (Dec. 27, 2021), as amended by section 1044 of the James M. Inhofe National Defense Authorization Act for Fiscal Year 2023, Pub. L. No. 117-263, 136 Stat. 2395, 2771-2 (Dec. 23, 2022).

DHA and NICoE officials said they also plan to repurpose the AHI Call Center at NICoE into an AHI Care Coordination Cell to centralize and streamline the AHI care experience. The AHI Care Coordination Cell would serve as a single point of contact for AHI patients, handling patient administration and registration, care site determination, case management, and clinical intake. Officials stated the Cell would also assist in the standardization of clinical care by providing patients a treatment plan that clearly lays out what they will receive

in the MHS. The AHI Care Coordination Cell, as envisioned, could potentially address several issues raised by patients like a lack of clear points of contact, inconsistent onboarding, and scheduling issues.

Other sub-tasks of the Plan could also potentially address patient concerns. For example, DHA is developing a Patient Identification Process intended to facilitate recognition of AHI patients at the front desks of facilities across the MHS. This process could potentially address patient concerns that MHS staff they encountered did not know how to look them up in their systems. Another element of the Plan calls for DHA to determine what durable medical goods AHI patients can receive and develop a strategy to communicate those decisions to patients. This step could potentially address uncertainty regarding durable medical good coverage and better manage patient expectations.

#### Planned Timeframes for Completion are Uncertain

Although these sub-tasks of DOD's Plan may address some patient access issues, their timeframes for implementation are uncertain. Between October 2023 and January 2024, DOD changed the projected timeframes for most of the Plan's seven high-level tasks to "To Be Determined." According to DHA officials, these changes reflect the uncertainty of completing certain key tasks, which other tasks rely on to move forward, such as data analysis and updated clinical guidance, in addition to tasks taking on additional complexity over time. For example, for the AHI registry task, they said that DOD is exploring adding individuals who sought AHI care outside of the MHS into the AHI registry, which will require DOD to consider how to seek consent from these individuals and house their medical records. As a result, DOD could not project specific completion dates for most of the tasks as of May 2024. However, despite the difficulties with projecting completion dates, DOD has made some implementation progress, and as of May, had reported completing 52 percent of the Plan, according to DHA officials (see table 2).

Table 2: Department of Defense (DOD) Plan of Action and Milestones Tasks with Projected Completion Dates for Anomalous Health Incidents (AHI) Care

Task Description	Projected Completion as of October 2023	Projected Completion as of May 2024	Task Completion as of May 2024 <sup>a</sup>
Communicate information to DOD personnel on how to seek evaluation and medical care for AHIs.	To Be Determined (TBD)	TBD	64 percent
Update the current distributed clinical guidance on screening, assessment, evaluation, and diagnosis of AHI with agreed-upon interagency processes.	Oct. 30, 2023	Sep. 30, 202	59 percent
Establish and maintain a clinical registry to aggregate all appropriate data on personnel from DOD and other federal departments and agencies who use the Military Health System (MHS) after being affected by an AHI.	Nov. 30, 2023	TBD	88 percent
Leverage data collection and analysis capabilities that support clinical care for personnel and inform research and intelligence efforts related to AHI.	Dec. 28, 2023	TBD	22 percent
Establish necessary processes and procedures to treat AHI patients at National Intrepid Center of Excellence, the Intrepid Spirit Center network, and other appropriate military medical treatment facilities as required, on a space-available basis.	Oct. 1, 2023	TBD	59 percent

Task Description	Projected Completion as of October 2023	Projected Completion as of May 2024	Task Completion as of May 2024 <sup>a</sup>
Develop the necessary categorical approvals or streamlined processes to accelerate the provision of appropriate medical treatment within the MHS, for authorized U.S. Government personnel and their dependents who may have been affected by AHIs.	Dec. 28, 2023	TBD	60 percent
Develop a long-term plan for the treatment and research of AHIs, which leverages potential partnerships with academic (public and private) institutions as appropriate.	TBD	TBD	10 percent
Overall Plan Status			52 percent

Source: DOD planning documents. | GAO-24-106593

Further, at the subtask level, DHA delayed full implementation of the AHI Care Coordination Cell to September 2024. Without the AHI Care Coordination Cell, AHI patients will likely continue to receive inconsistent scheduling and administrative support, potentially further delaying their access to medical care. Delayed access to care can also potentially lead to worsened health outcomes for AHI patients and hamper AHI research. The February 2022 intelligence community experts panel noted that prompt medical evaluation and care is particularly important for AHI patients, and that many individuals who received treatment immediately after an event have improved. DOD officials we spoke with linked prompt evaluation to better outcomes for AHI patients. In addition, an intelligence community experts panel noted early evaluation can also facilitate the gathering of medical information, such as symptoms and biomarkers that could help further research on AHI causes and treatment.

#### New Entry Process for Patients and AHI Care Cell Lack Monitoring Provisions

DOD's Plan does not contain any components for monitoring the timeliness of the Section 732 approval process or the performance of the enhanced AHI Care Coordination Cell after they are implemented. According to DHA officials, the Section 732 approval process contains the same 10-business day deadline as the current SECDES process. While DOD can monitor the progress of individual SECDES packages through its tasking system and a timeline sheet included with the package, according to a DOD official familiar with SECDES data, DOD does not systematically track the collective timeliness of the current SECDES package approval. Similarly, while DHA can track individual Section 732 approvals in its tasking system, the Plan has no provision for DHA to systematically track the overall timeliness of the Section 732 approval process.

DOD's Plan also contains no provision for DHA to monitor the performance of its proposed AHI Care Coordination Cell. DHA and NICoE officials acknowledged that the AHI Care Coordination Cell will rely, in part, on staff hired by the NICoE's current support contractor which has struggled to fill positions in a timely fashion. If past hiring difficulties persist, they could threaten the Cell's overall success.

Federal internal controls state that management should design control activities to monitor performance measures and indicators and document the results to identify control issues. Without overall monitoring, DOD will lack assurance that the Section 732 approval process is consistently meeting its 10-business day deadline. DOD also may be unable to determine where systematic process delays are occurring, to better address delays and get patients access to care more quickly. Likewise, without monitoring, DHA risks the success of its

<sup>&</sup>lt;sup>a</sup>According to a key DHA official, task completion percentages are calculated by averaging the completion percentages of the sub-tasks associated with a task, and overall plan status is calculated by averaging the completion percentages of the seven tasks. GAO has not independently verified the completion percentages.

planned AHI Care Coordination Cell, due to its reliance on a support contractor that has had difficulty hiring. Several of DHA's goals for AHI care, such as increased administrative support for patients and standardization of treatment, depend on a functional AHI Care Coordination Cell. Thus, lack of success with the Cell could jeopardize the success of the Plan, which could prolong and exacerbate existing patient challenges.

# AHI Registry Remains Under Development and Delays in Obtaining Consent Have Limited its Usefulness

DOD has modified the Trauma Registry as required by law to include certain data on AHI patients assessed or treated by DOD, but the AHI Registry data fields remain under development. Moreover, delays in obtaining individual consent for inclusion in the AHI Registry have limited the number of patients contained in it, limiting its usefulness. Furthermore, DOD lacks a long-term plan to gather consent from AHI patients who have completed their care in the MHS. Despite these limitations with the AHI Registry, DOD has been able to conduct some AHI research using other patient information.

## DOD Has Modified the Trauma Registry But is Still Developing the AHI Registry Data Fields

DOD has modified the Trauma Registry to gather information on AHI patients but is still developing the AHI Registry data fields. Section 732 of the FY 2022 NDAA, as amended, required DOD to modify the DOD Trauma Registry to include data on the demographics, condition-producing event, diagnosis and treatment, and outcomes of anomalous health conditions experienced by covered individuals assessed or treated under this section, subject to the consent of the covered individual and, if applicable, an agreement with the employing agency. DOD's Trauma Registry is a database that captures trauma data from the time service members are injured on the battlefield to when they receive treatment for care by providers within the United States, and the AHI Registry is a modification of it. According to a Senate report accompanying the FY 2023 NDAA, given the uncertainty of the long-term impacts on AHI victims, it is essential that DOD comprehensively record relevant AHI victim information for the purposes of, among other things, providing for a longitudinal record of health conditions, and informing improvement of care.<sup>23</sup>

The AHI Registry contains over 300 data fields that collect information on the AHI incident, patient demographics, symptoms, procedures and treatments used, and outcomes for patients as required by law. DOD originally planned to use a specific AHI form to gather the information to populate the AHI Registry, but medical providers have rarely used it. According to DOD officials, this form is an acute assessment tool designed to capture specific symptoms or markers that are most likely to be present in the first 7 days after an AHI incident. Most AHI patients do not see MHS providers within the first 7 days of their incident, making the form irrelevant for them. According to DOD officials, DHA has instead populated the registry using information contained in patient medical records, although officials noted that it takes substantial time to review and input these records. According to DHA officials, since AHIs are a poorly understood condition, DHA is still determining what information will be most useful for the AHI Registry. Therefore, DHA officials acknowledged they may need to add or delete fields as they learn more about AHIs. However, they noted that determining

<sup>&</sup>lt;sup>23</sup>S. Rep. No. 117-130 (2022).

which fields are most useful is complicated by the low number of patients entered in the registry due to both individual consent and agency agreement delays.

## Delays in Obtaining Individual Consent Have Limited the Number of AHI Patients Entered in the Trauma Registry

Section 732 of the FY 2022 NDAA, as amended, requires DOD to modify the Trauma Registry to include certain information on AHI patients assessed or treated by DOD, subject to the consent of the covered individual and, if applicable, an agreement with the employing agency. However, DOD was slow to seek consent from individual patients, absent a working registry, according to DOD officials. Additionally, key agencies have not signed Memorandums of Agreement (MOAs) with DOD agreeing to the inclusion of their employees in the registry, further slowing the inclusion of their employees, according to DOD officials.

According to DOD officials, DOD did not initially seek consent from SECDES patients to join the AHI Registry because DOD had not fully modified the Trauma Registry for AHI information. According to DHA officials, obtaining registry consent from individuals has been a major area of focus in 2024. DHA has developed an AHI Patient Registry FAQ for patients, and instructions for providers on asking for registry consent from new and legacy patients. Despite these steps, DOD officials acknowledged it has been difficult to contact patients who have left the MHS to obtain retroactive consent. DOD officials stated it is key that a trusted individual from DOD reaches out to former patients, as many AHI patients have had poor experiences with their employing agencies and may be hesitant to share information about themselves and their medical conditions. According to DOD officials, a CFT staff member who is well known to the AHI patients has conducted informal outreach. However, this individual's posting at the CFT ended in March 2024, and no long-term plan is in place to gather consent from individuals who have completed their care in the MHS. DOD has elected to obtain individual consent from patients first before requesting agency agreement.

Obtaining agency agreement has also contributed to slow entry of AHI patients into the registry. DOD has operationalized section 732 of the FY 2022 NDAA, as amended, by requiring agreement from the employing agency for all AHI patients who received care in the MHS before their information may be added to the AHI Registry. As of May 2024, the National Security Agency, the Defense Intelligence Agency, the Departments of Justice and Homeland Security, and the U.S. Agency for International Development had all signed MOAs with DHA granting agency permission to include their employees in the Trauma Registry. State has also signed an MOA with DHA. According to State officials, State has conferred agreement for inclusion of its employees in the registry. Additionally, the Undersecretary of Defense for Personnel and Readiness has provided general agency consent for DOD affiliated covered individuals, subject to some specific exceptions.

Agencies within the intelligence community have not signed MOAs, according to DOD officials. As of April 2024, employees of these agencies and their family members constituted 34 percent (88 of 257) of all AHI Secretarial Designees. For agencies without MOAs, DHA requests permission from the employing agency to include patients on a case-by-case basis after obtaining individual consent, according to DHA officials.

These delays have limited the number of individuals fully entered in the AHI Registry to 33 patients as of May 2024. As of January 2024, 334 people had qualified for AHI care in the MHS. According to officials, DHA has obtained individual consent and agency agreement for an additional 32 individuals, but their information has not been fully entered into the registry as it can take several days to go through an individual patient's records.

Without a plan to obtain retroactive consent from AHI patients, DHA will have a limited subset of patients in the AHI Registry to analyze. DOD officials stressed that a smaller number of patients could limit the usefulness of any findings, which may impair DOD's stated goals of understanding the underlying causes of AHIs and supporting the development of operational concepts to prevent and respond to such incidents.

Consent issues have also delayed other AHI care initiatives in DHA. According to DOD officials, DHA planned to have a data analytics team analyze AHI patient records to support process improvements to clinical care for AHIs. For example, the data analytics team planned to analyze pharmacy, radiology, and laboratory orders to better understand what providers are ordering for diagnosis and treatment of AHI patients within the MHS. However, because of legal uncertainty within DOD over whether the data analytics team could access these records without an agreement with the employing agency, this work has been delayed, according to DOD officials. While DHA officials stated they are working to resolve this uncertainty, DOD's Office of General Counsel has not reached a decision on this matter as of May 2024.

### DOD Is Able to Conduct Some AHI Research Using Other Data Sources

Despite limitations presented by consent issues, DOD is conducting some AHI research using other patient information. For example, NICoE leadership is conducting a retrospective and longitudinal review of AHI patients. For the retrospective portion, NICoE plans to examine the records of their AHI patients and are working with DHA's data analytics team to create controls against which to compare patients. For the longitudinal review, NICoE leadership plans to continue to evaluate the group of patients who went through the NIH study, in addition to other patients, and run additional tests on them over the next 2 to 3 years. The goal of this study is to examine relationships between demographics, neuropsychological assessments, neuroimaging, brain patterns, and other outcomes measures. NICoE will use these findings to develop and test new clinical criteria for measuring AHIs, create predictive models, and better understand long-term outcomes associated with AHIs.

DOD also has designed an Acute AHI Point of Injury Research Study that would examine the feasibility of reaching those potentially impacted by an AHI within 72 hours of an incident report. The study's staff would be on call to travel to DOD personnel and others affected by an AHI at or near their incident site in both domestic and overseas locations. After conducting tests on the affected individual, researchers would then find a demographically similar, but unaffected person at or near the incident to compare the individual against. According to the lead researcher, the study has received funding to respond to 20 AHI events. Another goal of the study is to gather data on potential AHI events in an event's early stage, and integrate the data with other DOD studies, such as the NICoE longitudinal study. According to DOD documentation, findings from this study will be shared with other components of DOD such as healthcare delivery, research, and the CFT.

DOD officials stated they are working on an MOA with State to potentially use embassy medical facilities. State officials acknowledged ongoing discussions with DOD on the feasibility of using these facilities and the development of a communication plan. According to DOD officials, if DOD and State cannot work out an arrangement, DOD plans to conduct the study solely on DOD personnel after moving them to DOD medical facilities.

### Conclusion

By providing medical care to current and former federal employees and their family members affected by AHIs, DOD has made a substantial difference in some patients' lives. Nevertheless, DOD is offering treatment for a poorly understood condition with unknown causes to a group of civilian beneficiaries with which the MHS has rarely dealt. As a result, many AHI patients we spoke with reported challenges accessing care in the MHS.

We recognize DOD cannot address challenges faced by all AHI patients prior to their entry into the MHS. However, DOD can address some patient challenges in the near term through better communication. Providing written guidance to AHI patients would help to standardize care, as well as set clear expectations for what treatment they will receive and how long they can expect to receive it. Establishing an official DOD channel for communicating authoritative information to AHI patients would allow DHA and the NICoE to alleviate many patient concerns, as well as provide a mechanism to explain procedures and changes in the MHS. Without such an official source of communication, AHI patients will continue to use informal networks that can potentially contain inaccurate information, create perceptions of inequities in medical treatment, and degrade trust in MHS providers.

DHA has developed a Plan for facilitating AHI care in the MHS that may address more patient concerns. For example, the new Section 732 approval process for AHI patients to enter the MHS could potentially provide faster access to treatment than the SECDES process. Additionally, the proposed AHI Care Coordination Cell could potentially address some of the more acute access and information concerns reported to us by AHI patients. However, DOD's timeframes to implement the Plan, including the care cell, are uncertain, which could prolong and exacerbate existing patient challenges.

Given the importance of these two Plan initiatives, DHA should incorporate monitoring into their implementation. The Section 732 approval process could promote better health outcomes for AHI patients by providing timely approval for evaluation and treatment of their symptoms. Thus, ongoing monitoring of the performance of the new process would help DHA ensure it is working as expected. The proposed AHI Care Coordination Cell could also facilitate timely access to care for AHI patients. Since the proposed Cell will continue to depend, in part, on a contractor that has struggled to hire patient support and care positions, ongoing monitoring of the performance of the Cell will help DHA ensure it is functioning as intended.

Finally, while DHA's AHI Registry can collect data required by legislation, it is unclear if it can conduct the kind of useful research needed to improve care for AHI patients. DHA states that it is working to develop more useful data fields for the registry. However, we note that such additional fields will not be useful unless DHA can include sufficient information from AHI patients in the registry in the first place. A long-term plan to obtain consent from patients who have completed their care in the MHS would expand the available information in, and ensure the eventual usefulness of, the registry.

## Recommendations for Executive Action

We are making the following six recommendations to DHA:

The Director of DHA should develop written guidance to facilitate AHI patient understanding of the MHS, such as through the handbook proposed in the Plan of Action and Milestones. (Recommendation 1)

The Director of DHA should establish a mechanism to systematically furnish official information to its AHI patients. (Recommendation 2)

The Director of DHA should fully implement the new care cell for AHI patients. (Recommendation 3)

The Director of DHA should add a monitoring component to the Plan of Action and Milestones on the new AHI entry process' timing. (Recommendation 4)

The Director of DHA should add a monitoring component to the Plan of Action and Milestones on the performance of the new care cell for AHI patients. (Recommendation 5)

The Director of DHA should develop a plan to gather AHI Trauma Registry consent from individuals who have finished their care in the MHS. (Recommendation 6)

## **Agency Comments**

We provided a draft of this report to DOD and State for comment. DOD provided comments that we have reproduced in appendix II. In its comments, DOD concurred with our recommendations and stated that it will take actions to implement them. For example, in response to recommendation 1, DOD stated that it is piloting an AHI welcome packet with plans for finalization in early fiscal year 2025. Additionally, in response to recommendations 4 and 5, DOD stated that it is developing monitoring capabilities for each of these initiatives with finalization projected for the first half of fiscal year 2025. DOD and State also provided technical comments that we incorporated as appropriate.

We are sending copies of this report to the appropriate congressional committees, the Secretary of Defense, and the Secretary of State. In addition, the report will be available at no charge on the GAO website at <a href="http://www.gao.gov">http://www.gao.gov</a>.

If you or your staff have any questions about this report, please contact me at (202) 512-8612 or at GianopoulosK@gao.gov. Contact points for our Office of Congressional Relations and Office of Public Affairs can be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix III.

Kimberly Gianopoulos

Managing Director, International Affairs and Trade

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## Appendix I: Objectives, Scope, and Methodology

This report examines (1) the challenges anomalous health incident (AHI) patients have faced accessing care in the military health system (MHS), (2) how the Department of Defense (DOD) is facilitating AHI patients' access to the MHS, and (3) the extent to which DOD has developed a Trauma Registry to facilitate AHI research.

To examine the challenges AHI patients have faced accessing care in the MHS, we conducted semi-structured interviews with 65 AHI patients from various federal entities on their experiences accessing the MHS. To solicit volunteers to be interviewed, we worked with cross-functional team (CFT) staff to distribute outreach messages through informal AHI patient networks. These messages explained the purpose of our review and provided both classified and unclassified means for patients to contact and be interviewed by the GAO team. We conducted these interviews both in-person and virtually in classified and unclassified venues. All 65 patients voluntarily contacted GAO to share their experiences. As such, their experiences and observations cannot be generalized to the broader AHI patient population. Additionally, while the CFT solicited volunteers for interviews, neither the CFT nor the interviewees' home agencies were privy to the identities of those who granted interviews to the GAO team.

Our interview cohort comprised 27 men and 38 women, 43 of whom had experienced their first AHI in 2019 or later. Twenty-six people experienced their AHI domestically, 35 people overseas, two people experienced AHIs in both domestic and overseas locations, and two people were unable to disclose or pinpoint a location. At the time of our interviews, 55 of these patients had obtained access to the MHS and 50 had begun receiving care. Of these 50, 28 patients primarily used the NICoE at Walter Reed, six people primarily used Fort Belvoir, 10 people primarily used other Defense Intrepid Network locations, while six reported using a combination of MHS facilities.

Where relevant, we asked all interviewees about their care experiences, to include the precipitating incident, immediate reporting and care seeking, initial access to the MHS, and treatment within the MHS. To analyze the challenges patients discussed in their interviews, we conducted a content analysis in two steps. In the first step, analysts read the interview notes and jointly developed categories for the interviews. In the second step, one analyst coded each interview, and then another analyst verified those codes. The analysts resolved any coding discrepancies by agreeing on what the codes should be. We did not evaluate the AHI reporting and referral processes of specific DOD components or other federal agencies as part of this review. However, we do include general findings on AHI patients' experiences with these processes to provide greater context for understanding the challenges faced by AHI patients prior to entering the MHS.

We obtained data from DOD on processing times for Secretarial Designee (SECDES) packages from July 2020 to April 2024. To assess the reliability of these data, we interviewed DOD officials, conducted standard outlier tests, and analyzed the variables for clear errors or missing data. We determined, based on these steps, that the data were sufficiently reliable for describing the general characteristics of the AHI SECDES cohort as well as the processing volume and timing of their paperwork.

To examine how DOD is facilitating AHI patients' access to the MHS, GAO reviewed DOD planning, guidance, and policy documentation and interviewed agency officials. For documentation, we reviewed DOD's Plan of Action and Milestones to identify the actions DOD is planning to take to advance access and care for AHI patients. We also examined several versions of DOD's Plan of Actions and Milestones (the Plan) as well as

#### Appendix I: Objectives, Scope, and Methodology

various deliverables to track implementation of specific tasks. An analyst examined the Plan's higher-level tasks and sub-tasks and compared these elements to access challenges reported by patients in our interviews. A second analyst reviewed this analysis and confirmed the results. Further, we interviewed cognizant DOD officials from the CFT, NICoE, and Defense Health Agency (DHA) about their perspectives on the Plan's progress. We also presented patient challenges reported to us to DOD officials, and discussed to what extent the Plan would address them.

To evaluate the extent to which DOD has developed a registry to facilitate AHI research, we reviewed DOD planning and data collection documentation and interviewed agency officials. For example, we examined DOD's collection tool for the registry to determine whether it was designed to gather information as required by law. We also reviewed the Memorandums of Agreement that DOD had signed with other agencies to gather agreement from the employing agency for the registry. We further reviewed the documents DOD uses to gather individual consent from patients, such as the consent form and AHI Trauma Registry FAQ document provided to patients. Finally, we interviewed knowledgeable officials from DHA, NICoE, CFT, and the Joint Trauma System about the steps DOD was taking to develop an AHI Trauma Registry and their efforts to gather individual and employing agency consent for the registry.

We conducted this performance audit from February 2023 to June 2024 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

# Appendix II: Comments from the U.S. Department of Defense



#### THE ASSISTANT SECRETARY OF DEFENSE

1200 DEFENSE PENTAGON WASHINGTON, DC 20301-1200

HEALTH AFFAIRS

July 12, 2024

Ms. Kimberly Gianopoulos Internal Affairs and Trade U.S. Government Accountability Office 441 G Street, NW Washington DC 20548

Dear Ms. Gianopoulos,

Attached is the Department of Defense (DoD) response to the Government Accountability Office (GAO) Draft Report GAO-24-106593, "Havana Syndrome: Better Patient Communication and Monitoring of Key DoD Tasks Needed to Better Ensure Timely Treatment" dated June 17, 2024 (GAO Code 106593).

My point of contact for this response is Ms. Kathy Lee who can be reached at Katherine.m.lee34.civ@health.mil and phone (703) 681-6133.

Sincerely,

MULLEN.SEIL Digitally signed by MULLEN.SEILEEN.MARI E.1519853007 Date: 2024.07.12 12:42:08-0400°

Lester Martínez-López, M.D., M.P.H.

Attachments: As stated

#### GAO DRAFT REPORT DATED JUNE 17, 2024 GAO-24-106593 (GAO CODE 106593)

## "HAVANA SYNDROME: BETTER PATIENT COMMUNICATION AND MONITORING OF KEY DOD TASKS NEEDED TO BETTER ENSURE TIMELY TREATMENT"

### DEPARTMENT OF DEFENSE COMMENTS TO THE GAO RECOMMENDATIONS

**RECOMMENDATION 1**: The Director of Defense Health Agency (DHA) should develop written guidance to facilitate Anomalous Health Incident (AHI) patient understanding of the Military Health System (MHS), such as through the handbook proposed in the Plan of Action and Milestones.

**Department of Defense (DoD) RESPONSE**: Concur. The DHA is enhancing awareness by developing patient-specific AHI knowledge products and resources to foster communication with patients.

The DHA is piloting an AHI Patient Welcome Packet at two facilities (Walter Reed National Military Medical Center and Alexander T. Augusta Military Medical Center), which provides newly established AHI patients with detailed information, including:

- An overview of AHI, an explanation of the AHI virtual screening process, and expectation setting for in-person evaluation.
- An introduction to the Defense Intrepid Network (DIN), including Intrepid Spirit Center (ISC) site-specific contact information and base access information.
- Tips for navigating the MHS, including contact information for the ISC, details on where
  the patient will receive care, and how to prepare for the first visit.
- Typical care team members, potential interdisciplinary services available throughout the ISC Network, criteria for understanding when treatment is considered "complete."
- How "space available care" impacts access to care and durable medical equipment.
- A checklist to prepare for the patient's first in-person appointment.

Once the pilot concludes in July 2024, feedback from AHI patients and participating ISC care team members will be incorporated, and the AHI Welcome Packet will be finalized by Quarter (Q)1 Fiscal Year (FY) 2025. The AHI Welcome Packet will be distributed to newly identified AHI patients before their first in-person AHI visit. In addition to the AHI Patient Welcome Packet, DHA is developing other knowledge products to target frequently raised topics such as the provision of durable medical equipment, navigating the MHS for non-DoD beneficiaries, and a high-level overview of AHI care available to patients.

These products will be disseminated via multiple channels, such as through the ISCs and AHI Care Coordinators, health mil and tricare mil, and United States Government Agencies. As further needs are identified from the AHI patient population, DHA will update and refine current

products and/or create new materials on an ongoing basis to address patient questions, concerns, and feedback

**RECOMMENDATION 2**: The Director of DHA should establish a mechanism to systematically furnish official information to its AHI patients.

**DoD RESPONSE**: Concur. The DHA will continue to provide a multifaceted approach to providing information to AHI patients. The DHA understands that non-DoD beneficiaries often have no experience with the MHS and require greater communication and guidance to effectively navigate the system. In June 2024, the DHA established a central location for AHI-specific, targeted patient knowledge products on health.mil and tricare.mil. The DHA is working to incorporate further methods to communicate the necessary information to ensure patients are aware of their care options and to limit the use of informal networks that may provide unreliable information

**RECOMMENDATION 3**: The Director of DHA should fully implement the new care cell for AHI patients.

**DoD RESPONSE**: Concur. The National Intrepid Center of Excellence's (NICoE) AHI Care Coordination Cell continues to provide care coordination for AHI patients across the DIN, including a dedicated Care Coordinator for patients and a dedicated phone line for both patients and providers.

**RECOMMENDATION 4**: The Director of DHA should add a monitoring component to the Plan of Action and Milestones on the new AHI entry process timing.

**DoD RESPONSE**: Concur. The DHA and NICoE continue to monitor the processing of patients referred under section 732 of the National Defense Authorization Act for FY 2022. To facilitate the timely processing of patient packages, the DHA has developed internal checklists and workflows to support referrals and to identify process steps and current gaps. To support interagency collaboration, the DHA continues to hold regularly occurring meetings with Agency staff and has provided Agencies with training and supporting materials regarding the section 732 process (to include a memorandum template for requesting AHI provision of care).

By Q1 FY 2025, the DHA will enhance current monitoring capabilities to include developing a systematic approach to track the AHI entry process verifying that the DHA can meet the 10-business day timeline to process section 732 patient packages, as well as NICoE's ability to meet the 28-business day timeline to schedule the initial patient screening. This capability will help the DHA to identify where process delays occur, allow for real-time mitigation strategies, and to provide more transparent communication between the DHA, patients, and Agencies. The DHA will continually review its capabilities to identify areas for process efficiencies, increase patient communication and outreach, and support overall patient satisfaction throughout the patient journey.

**RECOMMENDATION 5**: The Director of DHA should add a monitoring component to the Plan of Action and Milestones on the performance of the new care cell for AHI patients.

**DoD RESPONSE**: Concur. To assess the performance of the enhanced AHI Care Coordination Cell components, the DHA is developing monitoring mechanisms to include key performance indicators, monitoring performance, informing future processes and products, and allocating staff and resources by Q2 FY 2025. These monitoring mechanisms will allow for systematic and ongoing quality assurance processes on the utilization and impact of the AHI Care Coordination Cell, as well as the identification of potential improvement opportunities.

**RECOMMENDATION 6**: The Director of DHA should develop a plan to gather AHI Trauma Registry consent from individuals who have finished their care in the MHS.

**DoD RESPONSE**: Concur. The purpose of the AHI Patient Registry is to collect patient medical data for both DoD and non-DoD patients related to reported AHIs for analysis so that knowledge and characteristics of these incidents can be considered for further advancements in the diagnosis, treatment, and outcomes of AHI-affected individuals.

In March 2024, the DHA updated DHA Form 245, "Consent for Participation in AHI Registry," to streamline the process of consent for individuals who have finished their care in the MHS (i.e., "legacy patients") as well as the process for documentation of dual consent for new patients under section 732. This update allowed for a single avenue of consent for current and legacy patients. DHA Form 245 provided a telephone script to facilitate consistency of the consent process across sites. As of June 24, 2024, 67 individuals consented to participate in the AHI Patient Registry. Joint Trauma System personnel have abstracted data from 60 of the 67 consented patients into the AHI Registry. DHA will continue to actively seek consent of new and legacy AHI patients to the AHI Registry. The AHI Program Management Team will utilize a list of all legacy patients to monitor each ISC's progress monthly in contacting patients and documenting requests for consent.

To further support the consent process, the DHA disseminated specific AHI Registry knowledge products, such as an AHI Patient Registry of Frequently Asked Questions and AHI Instructions for Consenting Current and Legacy Patients, both via health.mil and directly to DHA staff.

# Accessible Text for Appendix II: Comments from the U.S. Department of Defense

July 12, 2024

Ms. Kimberly Gianopoulos Internal Affairs and Trade U.S. Government Accountability Office 441 G Street, NW Washington DC 20548

Dear Ms. Gianopoulos,

Attached is the Department of Defense (DoD) response to the Government Accountability Office (GAO) Draft Report GAO-24-106593, "Havana Syndrome: Better Patient Communication and Monitoring of Key DoD Tasks Needed to Better Ensure Timely Treatment" dated June 17, 2024 (GAO Code 106593).

My point of contact for this response is Ms. Kathy Lee who can be reached at Katherine.m.lee34.civ@health.mil and phone (703) 681-6133.

Sincerely,

MULLEN.SEIL EEN.MARIE.1 519853007

Digitally signed by MULLEN.SEILEEN.MARI E.1519853007 Date: 2024.07.12 12:42:08 -04'00'

Lester Martinez-López, M.D., M.P.H.

Attachments: As stated

**GAO DRAFT REPORT DATED JUNE 17, 2024 GAO-24-106593 (GAO CODE 106593)** 

"HAVANA SYNDROME: BETTER PATIENT COMMUNICATION AND MONITORING OF KEY DOD TASKS NEEDED TO BETTER ENSURE TIMELY TREATMENT"

DEPARTMENT OF DEFENSE COMMENTS TO THE GAO RECOMMENDATIONS

**RECOMMENDATION 1**: The Director of Defense Health Agency (DHA) should develop written guidance to facilitate Anomalous Health Incident (AHI) patient understanding of the Military Health System (MHS), such as through the handbook proposed in the Plan of Action and Milestones.

**Department of Defense (DoD) RESPONSE**: Concur. The DHA is enhancing awareness by developing patient-specific AHI knowledge products and resources to foster communication with patients.

The DHA is piloting an AHI Patient Welcome Packet at two facilities (Walter Reed National Military Medical Center and Alexander T. Augusta Military Medical Center), which provides newly established AHI patients with detailed information, including:

- An overview of AHI, an explanation of the AHI virtual screening process, and expectation setting for in-person evaluation.
- An introduction to the Defense Intrepid Network (DIN), including Intrepid Spirit Center (ISC) sitespecific contact information and base access information.
- Tips for navigating the MHS, including contact information for the ISC, details on where the patient will receive care, and how to prepare for the first visit.
- Typical care team members, potential interdisciplinary services available throughout the ISC Network, criteria for understanding when treatment is considered "complete."
- How "space available care" impacts access to care and durable medical equipment.
- A checklist to prepare for the patient's first in-person appointment.

Once the pilot concludes in July 2024, feedback from AHI patients and participating ISC care team members will be incorporated, and the AHI Welcome Packet will be finalized by Quarter (Q)1 Fiscal Year (FY) 2025. The AHI Welcome Packet will be distributed to newly identified AHI patients before their first in-person AHI visit. In addition to the AHI Patient Welcome Packet, DHA is developing other knowledge products to target frequently raised topics such as the provision of durable medical equipment, navigating the MHS for non-DoD beneficiaries, and a high-level overview of AHI care available to patients.

These products will be disseminated via multiple channels, such as through the ISCs and AHI Care Coordinators, health.mil and tricare.mil, and United States Government Agencies. As further needs are identified from the AHI patient population, DHA will update and refine current products and/or create new materials on an ongoing basis to address patient questions, concerns, and feedback.

**RECOMMENDATION 2:** The Director of DHA should establish a mechanism to systematically furnish official information to its AHI patients.

**DoD RESPONSE**: Concur. The DHA will continue to provide a multifaceted approach to providing information to AHI patients. The DHA understands that non-DoD beneficiaries often have no experience with the MHS and require greater communication and guidance to effectively navigate the system. In June 2024, the DHA established a central location for AHI- specific, targeted patient knowledge products on health.mil and tricare.mil. The DHA is working to incorporate further methods to communicate the necessary information to ensure patients are aware of their care options and to limit the use of informal networks that may provide unreliable information.

**RECOMMENDATION 3**: The Director of DHA should fully implement the new care cell for AHI patients.

**DoD RESPONSE**: Concur. The National Intrepid Center of Excellence's (NICoE) AHI Care Coordination Cell continues to provide care coordination for AHI patients across the DIN, including a dedicated Care Coordinator for patients and a dedicated phone line for both patients and providers.

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# Appendix III: GAO Contact and Staff Acknowledgments

#### **GAO Contact**

Kimberly Gianopoulos, (202) 512-8612 or GianopoulosK@gao.gov

### Staff Acknowledgments

In addition to the contact named above, Robert Ball (Assistant Director), David Hancock (Analyst-in-Charge), Eric Smith, Pamela Davidson, Neil Doherty, Aldo Salerno, and Alex Welsh made key contributions to this report.

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## Strategic Planning and External Liaison

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