



## Cluster Headache Study

VHA EPRP FY2022

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## Cluster Headache

- A primary headache disorder and the most common of the group of headache disorders called trigeminal autonomic cephalalgias.
- The term cluster headache comes from the fact that these attacks occur in groups, or “clusters.”
- During a cluster cycle, brief, excruciatingly severe headache attacks recur between 1-8 times per day.
  - Cluster cycles can last for weeks or months and are usually separated by remission periods, or periods of headache freedom, which usually last months or years. People who experience chronic cluster headache have no remission periods, or the remissions last less than a month at a time.
- **Cluster headache is often said to be the most painful of all headaches;** it has been described as “boring,” “burning,” “like a hot poker in the eye” and as “suicide headache.”
- Cluster headache is more common in males



## Cluster Headache Characteristics

- **Location:** Unilateral orbital or retro-orbital
- **Severity:** severe to extremely severe
- **Duration:** < 3 hours if untreated
- **Rarely:**
  - light sensitivity
  - has aura
  - has nausea/vomiting



## Veterans and Cluster Headache

- **FY2009 - FY2019**
  - 24,131 Veterans had clinical encounter where cluster headache (CH) diagnosis was given
  - 5,767 were classified as chronic CH
  - 13,075 as having unspecified CH



## Initial Work

- Completed test abstraction on sample of 100 cases in December 2021
- Results and feedback provided to study sponsors
- After thorough review, changes were made to the data collection tool and sampling methodology



## Informational Study

- The sample includes 1,200 visits of patients seen by primary care or neurology provider during a three year period (fiscal years 2016, 2017 or 2018) and who had at least three years of follow-up
- The initial visit is related to diagnosis of cluster headache; subsequent visits can be for any type of headache
- Cases are assigned to index VAMC where initial visit for headache occurred
- Follow-up encounters may occur at other VAMCs



## Sex (Gender)

- Note: The patient's sex was not sent on the pull list and will need to be entered

- 1 – Male
- 2 – Female
- 3 – Unknown

ADMIN	HAENCDDT	HATYPE1	HATYPE11	HATYPE21	HATYPE31	HALOC	HASE
VAMC:	901	QIC:					
Control Number:	1223457504	MODIFY DATE:					
Patient Name:	TAbarca, A	REVIEW BEGIN DT:	11/18/2021 12:01:02 PM				
Sex:		PATIENT SSN (Last 4):	918274764				
Marital Status:							
Race:							
BIRTHDATE:	01/28/1947						



## Initial Encounter

- First two questions will be pre-filled and cannot be modified
- Q1 haencdt: date of earliest outpatient encounter with physician/APN/PA related to cluster headache during the timeframe from October 1, 2015 through September 30, 2018
- Q2 haenc1sta: facility (station) where visit occurred



## Validation of Initial Encounter

- New question added based on test abstraction
- Q3 valhaenc: On (computer to display haencdt) is there documentation of an outpatient encounter with a physician/APN/PA for cluster headache?
  1. Yes
  2. No



## Valhaenc cont'd

- Select value "1" if the patient had an outpatient encounter with a physician/APN/PA for cluster headache on the pre-filled date.
- Include only outpatient encounters.** An outpatient encounter may include:
  - Face-to-face visit
  - Telehealth visit
  - Telephone note
  - e-Consult only where the patient is seen by a Physician/APN/PA
- Exclude:**
  - Encounters that were for the purpose of procedures only such as electroencephalograms (EEGs) or Magnetic Resonance Imaging (MRI)
  - Telephone calls to inform patient of test results.
  - Provider to provider encounters where the patient is not present
  - Encounters at non-VHA facilities



## Initial Encounter Back up Visit

- Questions 4 and 5 (othancdt1 and ohaenc1sta) will be pre-filled from the pull list**
- Q6 valhaenc1 asks you to validate the pre-filled encounter date at the specified facility (ohaenc1sta)
- Same definition/decision rules as q3 valhaenc
- If the patient did not have an outpatient encounter for cluster headache with a physician/APN/PA on the specified date at specified facility, the case will be excluded.



## InitialEncounterDate

- Depending on which pre-filled encounter was validated, the subsequent questions will display the date from HAENCDDT or OTHAENDT1
- This is labeled as InitialEncounterDate in the question



## Visit Type

- Q7 vis1type: Was the encounter on (computer to display InitialEncounterDate) conducted virtually or in person?
  1. VA Video Connect (VVC)
  2. Clinical Video Telehealth (CVT)
  3. Telephone
  4. In person



## Health care provider type

- Q8 hcp1type: During the outpatient encounter on (computer display InitialEncounterDate), what type of health care provider did the patient see for cluster headache?
  1. 300 – Primary Care, attending physician without resident
  2. 300 – Primary Care, attending physician with resident
  3. 301 – Primary Care APN/PA
  4. 302 – Neurology, attending physician without resident
  5. 303 – Neurology, attending physician with resident
  6. 304 – Neurology, APN/PA
  99. None of the above



## Clinical Impression of Headache Type(s)

- Q9 hatype: During the outpatient encounter on (computer to display InitialEncounterDate), what is the clinical impression of the type(s) of headache documented by the provider? **[Select all that apply]**
- **Numerous options**
- **Note:** The first type of headache is typically the most severe type, which is why patients present to the attention of a healthcare provider.
- Please look in the assessment and plan/impression and recommendations section of the provider note regarding the clinical impression of the type(s) of headache the patient has and select accordingly.



## Headache Characteristics

- Next few questions pertain to InitialEncounterDate
- **Please read the entire encounter note and answer the question accordingly**
- Q10 haloc1: During the outpatient encounter on (computer display InitialEncounterDate), what is the location of the patient's headache pain documented by the physician/APN/PA?
- **Select all that apply:**
  1. Orbital
  2. Supraorbital
  3. Retroorbital
  4. Periorbital
  5. Temporal
  6. Location elsewhere
  99. No location documented



## Headache on Same Side

- Q11 haside: During the outpatient encounter on (computer display InitialEncounterDate), are the headache attacks always on the same side of the head (in a given cycle for episodic patients)?
  1. Yes
  2. No, headache attacks are not always on the same side
  99. No documentation
- **Note:** The 99 option should only be selected if there is no documentation in the note regarding the consistency of side of the headache pain.



## Headache Severity

- Q12 havev: During the outpatient encounter on (computer display InitialEncounterDate), is the headache attack severe or very severe or synonyms thereof?
  1. Yes
  2. No, headache attack is described as less than severe
  99. No documentation
- Documentation such as disabling, crushing, worst pain in world, can also be used to select value "1."
- If yes (1) is selected, the words used to describe severity will be entered in text field (q13, havevwd)



## Presence of Symptoms during Attack

- Q14 hasymp: On (computer display InitialEncounterDate) are any of the following symptoms documented as present during the headache attack?
- **Select all that apply:**
  1. Ipsilateral conjunctival injection (blood shot eye)
  2. Lacrimation (secretion or shedding of tears)
  3. Nasal congestion
  4. Rhinorrhea (runny nose)
  5. Eyelid edema
  6. Forehead or facial sweating
  7. Miosis (constriction of the pupil)
  8. Ptosis (drooping of upper eyelid)
  99. None of the above



## Symptoms NOT Present

- Q15 hanosymp1: On (computer display InitialEncounterDate) are any of the following symptoms documented as NOT present during the headache attack or is there documentation of "no autonomic symptoms"?
- **Select all that apply:**
  1. Ipsilateral conjunctival injection (blood shot eye)
  2. Lacrimation (secretion or shedding of tears)
  3. Nasal congestion
  4. Rhinorrhea (runny nose)
  5. Eyelid edema
  6. Forehead or facial sweating
  7. Miosis (constriction of the pupil)
  8. Ptosis (drooping of upper eyelid)
  9. "No autonomic symptoms"
  99. None of the above



## Q15 Symptoms NOT Present

- Please read the physician/APN/PA note for the specified date of the encounter related to cluster headache to determine if there is documentation any of the listed symptoms are NOT present.
- If the physician/APN/PA documents any of the listed symptoms are NOT present, select the applicable value(s).
- Please answer 9 only if it is noted that there are NO autonomic symptoms.



## Headache Frequency

- Q16 hanum: During the encounter on (computer display InitialEncounterDate) is there evidence in the medical record that the patient had a total of more than five (5) headache attacks during their lifetime?
  1. Yes
  2. No, there is evidence of five (5) headache attacks or less during their lifetime
  99. No documentation
- Look for documentation in the note that the patient had a total of more than five (5) headache attacks during their lifetime
- The exact number does not have to be documented. For example, patient reported daily headaches for two weeks = 14 headache attacks, answer "yes"



## Headache Duration

- Q17 hadur: On (computer display InitialEncounterDate), is the usual duration of a headache attack between 15 to 180 minutes?
  1. Yes
  2. No, headache attacks are not between 15-180 minutes
  99. No documentation
- Example: Physician notes, "Patient reports headache duration is typically 30 minutes;" enter 1.
- PA notes, "Usual HA duration is 6 hours;" enter 2.



## Minimum and Maximum Duration

- Q18 hamindur: What is documented minimum duration of an attack?
  1. Less than 15 minutes
  2. Between 15 to 90 minutes
  3. Between 91 to 180 minutes
  4. Between 180 to 360 minutes
  5. Between 6 and 12 hours
  6. More than 12 hours
  99. No minimum duration documented
- Q19 hamaxdur: What is documented maximum duration of an attack?
  1. Less than 15 minutes
  2. Between 15 to 90 minutes
  3. Between 91 to 180 minutes
  4. Between 180 to 360 minutes
  5. Between 6 and 12 hours
  6. More than 12 hours
  99. Not documented



## Attack less than 15 minutes

- Q20 haminrar: On (computer display InitialEncounterDate), is a headache attack of less than 15 minutes documented as being rare or usual?
  1. Rare (or unusual)
  2. Usual (or typical)
  99. Not documented



## Abortive Medication or Treatment

- Q21 hatreat: During the encounter for headache on (computer display InitialEncounterDate), were headaches lasting less than 15 minutes reported to have been treated with an abortive medication or other abortive treatment?
  1. Yes
  2. No, headaches were not treated with abortive medication or treatment
  99. No documentation
- **Abortive treatments for headache are medications or other treatment that can help stop a headache once it starts.**



## Abortive Treatments

- **Abortive treatment may include prescription or over the counter medications, headache devices such as GammaCore or nVNS, oxygen, action by the patient such as exercise or use of cold therapy (e.g., ice pack).**
- Examples of abortive medications for headache include Triptans (e.g., almotriptan [Axert<sup>®</sup>], eletriptan [Relpax<sup>®</sup>], frovatriptan [Frova<sup>®</sup>], naratriptan [Amerge<sup>®</sup>], rizatriptan Maxalt<sup>®</sup>), sumatriptan [Imitrex<sup>®</sup>], zolmitriptan, [Zomig<sup>®</sup>]), opioid medications, and ibuprofen.



## Abortive Medications and Treatment

- Q22 hatxmed: During the encounter for headache on (computer display InitialEncounterDate), select all abortive medications and/or abortive treatment the patient takes or used for headaches.
- **Select all that apply:**
  1. Triptans (see list in D/D rules)
  2. Opioids (see list in D/D rules)
  3. Ibuprofen
  4. Other abortive medication
  5. Oxygen
  6. Exercise
  7. Cold (e.g., ice pack)
  8. Other abortive treatment (e.g., GammaCore, nVNS)



## Headache Attack Duration 180 minutes or greater

- Q23 hamaxrar4: On (computer display InitialEncounterDate), is an attack between 180 to 360 minutes documented as being rare or usual?
  1. Rare (or unusual)
  2. Usual (or typical)
  99. Not documented
- Q24 hamaxrar5: On (computer display InitialEncounterDate), is an attack greater than 6 hours documented as being rare or usual?
  1. Rare
  2. Usual
  99. Not documented



## Headache Frequency

- Q25 hafreq: On (computer to display InitialEncounterDate), what is the usual frequency of headache attacks?
  1. One attack occurring every 3 days or more than 3 days
  2. One attack occurring every 1-2 days
  3. 2-4 attacks per day
  4. 5-8 attacks per day
  5. More than 8 attacks per day
  99. Not documented



## Other Headache Characteristics

- Q26 hacycle: On (computer display InitialEncounterDate), do headaches occur only certain times of year?
  1. Yes
  2. No, headaches occur throughout the year
  99. No documentation
- Cluster headaches may occur in cycles or periods during certain times of the year
  - Example: Physician noted, “patient reported headache attacks usually occur in spring and fall;” select value 1.



## Same time of day or night

- Q27 hatmdy: On (computer display InitialEncounterDate), do the individual headaches occur at the same time (day or night)?
  1. Yes
  2. No, headache attacks occur throughout the day at different times.
  99. No documentation
- Example: Physician noted, “patient reported headaches usually occur after going to bed and he wakes up due to pain around 3:00 AM;” select value 1.



## Remission Periods

- A remission period is a period of time when no cluster headache attacks occur.
- Q28 harem: On (computer display InitialEncounterDate), are there remission periods lasting for 3 months or longer when no cluster headache attacks occur?
  1. Yes
  2. No, there are no remission periods or remission periods last less than 3 months
  99. No documentation
- Example: Physician noted, “patient reported no headaches occurred from January through April;” select value 1.
- If physician/APN/PA documents no remission periods or that remission periods last less than 3 months, select value 2.



## Other Symptoms and Concerns

- Q29 haagi: On (computer display InitialEncounterDate) is there associated restlessness or agitation during any of the headache attacks?
  1. Yes
  2. No, there is not restlessness or agitation during headache attacks (could be stated that when patient gets the headache that they like to rest or lie down)
  99. No documentation
- Please read the physician/APN/PA note for the specified date of the encounter related to cluster headache to determine if there is documentation of associated restlessness or agitation during any of the headache attacks.
- If physician/APN/PA documents there is no restlessness or agitation during the headache attacks, for example, “When patient gets the headache they like to rest or lie down”, select value 2.



## Self Injury

- Q30 sefinj: On (computer display InitialEncounterDate) was there any assessment of self-injury during a cluster headache attack any time in the patient’s lifetime?
- Self-injury may include but it not limited to: banging or hitting their head, punching the wall, or biting extremities, such as their hand during the cluster headache attack.
  - Example: Physician asks the patient, “Have you ever hurt or injured yourself during a headache attack?” Select value 1.



## Self injury cont’d

- Q31 sefinjdne: On (computer display InitialEncounterDate), was there documentation of self-injury carried out during a cluster headache attack any time in the patient’s lifetime?
  1. Yes
  2. No history of self-injury during a headache attack
  99. No documentation
- Look for documentation of terms such as banging or hitting their head, punching the wall, or biting extremities, such as their hand during the cluster headache attack
- If yes→Q32 sefinjact: Enter the documented self-injury.



## Suicide Risk Assessment

- **Questions 33 – 42 are only asked for the initial visit for headache**
- **Q33 asemi:** During the outpatient encounter on (computer display InitialEncounterDate), was the patient asked about suicidal thoughts or ideation?
  - **Examples of suicidal thoughts include but are not limited to:** thoughts of killing self; thoughts of wishing oneself was dead
- Suggested data sources: Physician Progress notes, Nursing Notes



## Suicide Risk Assessment cont'd

- **Q34 docsi:** During the outpatient encounter on (computer display InitialEncounterDate) did the patient have suicidal thoughts?
  1. Yes
  2. Patient did not have suicidal thoughts
  99. No documentation
- Suicidal thoughts could have occurred at any time
- If the physician/APN/PA or RN documents the patient had any suicidal thoughts, select "1."
- If the physician/APN/PA or RN documents the patient did not have any suicidal thoughts, select "2."



## Suicidal Thoughts documented

- **Q35 siinfo:** Enter the nature of the suicidal thoughts.
  1. Wishing they were dead
  2. Wishing they could go to sleep and not wake up
  3. Wanting to kill themselves
  4. Planning to kill themselves
- Select the appropriate value most closely representing the nature of the patient's suicidal thoughts.
- If value 4 selected → **Q36 siplan:** Enter the method of harm indicated by the patient as documented in the record.



## Active Suicidal Thoughts

- **Q37 actsi:** During the outpatient encounter on (computer display InitialEncounterDate), did the patient have **active** suicidal thoughts?
  1. Yes
  2. No **active** suicidal thoughts
  99. No documentation
- Active suicidal thoughts means that the patient indicated to the physician/APN/PA that he/she currently has thoughts of harming oneself
- **If yes → q38 acsiinfo:** Enter the value corresponding to nature of the **active** suicidal thoughts:
  1. Wishing they were dead
  2. Wishing they could go to sleep and not wake up
  3. Wanting to kill themselves
  4. Planning to kill themselves
- **Q39 acsplan:** Enter the method of harm indicated by the patient as documented in the record.



## Suicide Attempts

- **Q40 asesiatmp:** During the outpatient encounter on (computer display InitialEncounterDate), did the physician/APN/PA or RN **ask** the patient about suicide attempts?
  1. Yes
  2. No
- In order to select "1", the physician/APN/PA or RN must document they asked the patient about suicide attempts during the encounter on the specified date.



## Attempted Suicide

- **Q41 suiatmp:** During the outpatient encounter on (computer display InitialEncounterDate), did the patient ever attempt suicide?
  1. Yes
  2. No history of suicide attempt (meaning that it is stated that there is no history of suicide attempt)
  99. No documentation
- **If yes → q42 atmpinfo:** Enter the nature of the suicide attempt.



## Follow up Headache Encounters (begins with q43 haencdt2)

- The tool includes question sets for up to three follow-up encounters
- The date of the follow-up encounter (e.g., haencdt2) and the facility ID (e.g., haencsta2) will be pre-filled
- **Follow up encounters may occur at other facilities so note the facility ID and review accordingly**
- The questions for each encounter are the same except the Suicide Risk Assessment questions (33 – 42) are not asked for follow-up encounter(s)



## Follow-up encounters cont'd

- Third outpatient encounter for headache:
  - q73 haencdt2 to q102 sefinjact3
- Fourth outpatient encounter for headache:
  - q103 haencdt4 to q132 sefinjact4



## Summary

- Informational study to collect data on care provided to veterans with initial diagnosis of cluster headache
- No DACs or exit report
- Pull list will be released on May 9
- **Abstraction due date is June 21, 2022**



## Questions

- Please direct any questions that arise to me ([asites@qualityinsights.org](mailto:asites@qualityinsights.org)) and your Regional Manager
- Thank you for your attention and excellent work!

