Hydrocephalus surveillance following shunt placement or endoscopic third ventriculostomy: a survey of surgeons in the Hydrocephalus Clinical Research Networks
Hersh et al.

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Appendix 1. Survey Instrument

Demographics
1. How many years have you been in practice (not including training)?
   a. 1-5
   b. 6-10
   c. 11-20
   d. >20

2. Approximately how many patients with hydrocephalus do you see in the office or clinic in a given year?
   a. Less than or equal to 50
   b. 51-100
   c. 101-200
   d. Greater than 200
   e. Unknown

3. What is the age range of patients in your practice?
   a. Pediatrics only (0 to 18 years or less)
   b. Pediatrics only (0 to mid-20s or less)
   c. Pediatrics and adults
   d. Adults only
   e. Other (please elaborate)

4. Do you and your partners follow the same surveillance protocol for patients with hydrocephalus?
   a. Yes, my partners and I follow the same protocol
   b. No, my partners and I differ in our surveillance
   c. N/A – I am the only one in my practice
   d. Other (please elaborate)

5. Are you a member of the HCRN or HCRNq?
   a. HCRN
   b. HCRNq
   c. Unknown

Shunt Surveillance
1. After a shunt placement or revision, when do you consider the patient’s hydrocephalus to have "stabilized"?
   a. 1 month
   b. 3 months
   c. 6 months
   d. 12 months
   e. Other (please elaborate)

2. After reaching "stability" how often do you ask a patient to return for routine clinical follow-up?
   a. Every 6 months
   b. Every 12 months
   c. Every 2 years
   d. I don’t ask for routine follow-up
   e. Other (please elaborate)
3. After a shunt placement or revision, when do you think that routine clinical follow-up is no longer necessary?
   a. 1 year
   b. 2 years
   c. 5 years
   d. 10 years
   e. Never
   f. Other (please elaborate)

4. Do you ever obtain “routine” imaging studies in an asymptomatic patient?
   a. Yes
   b. No

5. Which imaging studies do you obtain routinely? (Check all that apply)
   a. Head CT
   b. Brain MRI
   c. Shunt series
   d. Other (please elaborate)

6. How frequently?

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<tr>
<th></th>
<th>Every 6 months</th>
<th>Every 12 months</th>
<th>Every 2 years</th>
<th>Other</th>
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<tbody>
<tr>
<td>Head CT</td>
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<td>Brain MRI</td>
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<td>Shunt Series</td>
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<td>Other</td>
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7. What is your first step in management of an asymptomatic patient with an increase in ventricle size on a routine scan?
   a. No change to my routine follow-up
   b. More frequent observation
   c. Shunt series
   d. Shunt tap +/- shunt flow study (e.g. contrast study or nuclear medicine study)
   e. Shunt exploration
   f. Other (please elaborate)

8. What is your next step if the shunt series demonstrates an intact shunt?
   a. No change to my routine follow-up
   b. More frequent observation
   c. Shunt tap +/- shunt flow study (e.g. contrast study or nuclear medicine study)
   d. Shunt exploration
   e. Other (please elaborate)

9. What is your next step if the shunt series demonstrates a fractured shunt?
   a. No change to my routine follow-up
   b. More frequent observation
   c. Shunt tap +/- shunt flow study (e.g. contrast study or nuclear medicine study)
   d. Shunt exploration
   e. Other (please elaborate)

10. What is your initial approach to an asymptomatic patient with a fractured shunt catheter on a routine shunt series?
    a. No change to my routine follow-up
    b. More frequent observation without cranial imaging
c. Cranial imaging (head CT or MRI)
d. Shunt flow study (e.g. contrast study or nuclear medicine study)
e. Shunt externalization and clamp trial
f. Shunt revision
g. Other (please elaborate)

11. What is your next step if the patient’s ventricles are stable and the patient is asymptomatic?
   a. No change to my routine follow-up
   b. More frequent observation
c. Shunt flow study (e.g. contrast study or nuclear medicine study)
d. Shunt externalization and clamp trial
e. Shunt revision
f. Other (please elaborate)

12. What is your next step if the patient’s ventricles are enlarged and the patient is asymptomatic?
   a. No change to my routine follow-up
   b. More frequent observation
c. Shunt flow study (e.g. contrast study or nuclear medicine study)
d. Shunt externalization and clamp trial
e. Shunt revision
f. Other (please elaborate)

ETV Surveillance

1. After an endoscopic third ventriculostomy, when do you consider the patient’s hydrocephalus to have “stabilized”?
   a. 1 month
   b. 3 months
c. 6 months
d. 12 months
e. Other (please elaborate)

2. After reaching “stability” how often do you ask a patient to return for routine clinical follow-up?
   a. Every 6 months
   b. Every 12 months
c. Every 2 years
d. I don’t ask for routine follow-up
e. Other (please elaborate)

3. After an ETV, when do you think that routine clinical follow-up is no longer necessary?
   a. 1 year
   b. 2 years
c. 5 years
d. 10 years
e. Never
f. Other (please elaborate)

4. Do you ever obtain “routine” imaging studies in asymptomatic patients?
   a. Yes
   b. No

5. Which imaging studies do you obtain routinely? (Check all that apply)
   a. Head CT
   b. Brain MRI
c. Other (please elaborate)

6. How frequently?

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<tr>
<th></th>
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<td>Head CT</td>
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<td>Brain MRI</td>
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<td>Other</td>
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7. How do you manage an asymptomatic patient with an increase in ventricle size on a routine scan?
   a. No change to my routine follow-up
   b. More frequent observation
   c. Endoscopic exploration
   d. Shunt placement
   e. Other (please elaborate)
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<tr>
<th>Question</th>
<th>“Other” free-text responses</th>
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<tbody>
<tr>
<td>Do you and your partners follow the same surveillance protocol for patients with hydrocephalus?</td>
<td>I’m not sure frankly&lt;br&gt;Mostly same. I think I see patients and image more frequently during infancy, but for the most part we have similar practice/surveillance patterns&lt;br&gt;I do not know what surveillance protocol my colleagues follow</td>
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| After a shunt placement or revision, when do you consider the patient's hydrocephalus to have 'stabilized'? | New shunt is different than revision. How to define "stabilize": if it means to reach stable ventricular/brain volume, will vary with age. If define as low pressure enough that the head stops growing or symptoms reverse, different. cannot answer without greater precision<br>Very age-dependent, and differs between initial shunt placement and revisions<br>Variable<br>I don't consider it "stabilized."
<p>|                                                                                           | After revision, I consider it stabilized immediately. After initial placement, it depends on the age. Older kids with acquired hydro, it's probably immediate. Babies with congenital severe hydro, it can take months or years for the brain to fill in. Depends&lt;br&gt;Depends on the age, severity, whether placement or revision&lt;br&gt;When imaging demonstrates that ventricles have not changed on two successive scans and clinical manifestations are absent&lt;br&gt;Depends on patient age and diagnosis&lt;br&gt;It depends on age. For infants, it may take years. Usually, a month or two. |
| After reaching 'stability' [following a shunt], how often do you ask a patient to return for routine clinical follow-up? | Every 6 months age 0-5 years, annually until 18, then every other year&lt;br&gt;Infants and young children are typically seen yearly; older children without recent problems typically come every two years&lt;br&gt;Variable based on age and time from surgery&lt;br&gt;Depends on age, q 3months for &lt;1, q6 months for 1-2, q1 yr till age 18 then q2 yrs&lt;br&gt;Every 6 months until 2 years old then in general once a year&lt;br&gt;Depends on age, q year when younger, may space out when older&lt;br&gt;When young (&lt;5 years), yearly. Older children who have been stable, q2 years.&lt;br&gt;q 1 year and then q 2 years&lt;br&gt;Depends on age of patient (younger = more frequent)&lt;br&gt;for infants q6 mo until 2 then yearly&lt;br&gt;Depends on the patient age. Annual if 5 years or less, biannual 5 and over&lt;br&gt;Every 12 mo until 5 years of age, then q 2-3 years&lt;br&gt;First few years on yearly basis, then gradually increase interval to prn&lt;br&gt;Depends on patient age and diagnosis&lt;br&gt;Every 6 months until age 5, then every year&lt;br&gt;Young patients once a year, older patients prn&lt;br&gt;Depends on age of patient and time from surgery |
| After a shunt placement or revision, when do you think that routine clinical follow-up is no longer necessary? | Variable based on age and time from surgery&lt;br&gt;Only if the shunt is shown to be nonfunctional for 5 years&lt;br&gt;After 21 years of age&lt;br&gt;We don’t do routine follow-up&lt;br&gt;I transition them to adult care between 18 and 21.&lt;br&gt;Depends on age of patient.&lt;br&gt;For non-spina bifida patient, once adulthood is reached, follow can be PRN&lt;br&gt;I typically follow all pediatric patients with hydrocephalus periodically. I also see some adult patients periodically but also give them the option of p.r.n. visits&lt;br&gt;When adult&lt;br&gt;Not sure the answer - depends on patient, parents, where they live etc. |
| Which imaging studies do you obtain routinely [following a shunt]? | Rapid limited MRI with T2 sequences alone&lt;br&gt;Head ultrasound&lt;br&gt;Depends on geography (CT if their home community only has CT, MR if community has MR) |
| How frequently is a head CT obtained [following a shunt]? | 5 years&lt;br&gt;10 years to ensure baseline image available for other providers who might care for patient |</p>
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<tr>
<td>How frequently is a brain MRI obtained [following a shunt]?</td>
<td>Every 3-6 months till stable ventricles on serial studies, then q 5 years. 5 years to ensure baseline image available for other providers who might care for patient. Limited Sequence MRI at 6 weeks and around 12 months following surgery, then 2 years. For stable asymptomatic patients I get a CT or MRI every five years. Usually will have baseline at about a year out, and then only as needed. 6-12 weeks post-revision for new baseline. Every 5 y if pt verbal. Age dependent, yearly in younger, less frequent in older. I only obtain asymptomatic imaging if a patient has not had imaging in several years (greater than 2 year, closer to 5 depending on age and history). Baseline when asymptomatic. It varies. Once 6 months later for a steady-state. I get a T2 or a HCT about age 2-3 as I find the vents change a lot in that interval and what is &quot;normal&quot; in infancy can have smaller vents and be a failure scan at age 4. Yearly during infancy, early childhood then q 2-3 yrs and after a few stable scans then only clinical f/u if asymptomatic. Specifically for infants with a shunt, imaging is obtained between 1-2 years for 'baseline'. Depends on age. &lt;5yrs annual, 5-10 biannual, &gt;10 only at age 15 then final at 18. We use rMRI and image with clinical surveillance mentioned above. After shunt placement q 3 mom until at baseline. One scan at 1 year, then at 2 years, then at 5 years, and then only if new symptoms. 3 months and 1 year post op then prn for symptoms. Same as for CT, would depend on ventricular morphology. Asymptomatic it would be if general suspicion, if not imaged in a long time, if the family asks for a picture. Depends on patient age and diagnosis. Every 3-5 years. Until 8-10 years, yearly. Older and teenagers, every 2 years. 12 month scan after any revision or placement then every two years thereafter if no symptoms. Make sure there is a baseline study within the past 5 years. Annually for 5 or less years old, every two or three years as they get older. 12m until 5y then 2y if stable thereafter. Every year for 5 years, then every 3-5 years thereafter. 5 years. 5 years. 4-5 years. Several years. CT vs limited MRI depends upon individual clinical situations. 5 scans from infancy to adulthood. Every 5 years, if not already done.</td>
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<td>How frequently is a shunt series obtained [following a shunt]?</td>
<td>After puberty / growth spurt. 10 and 15 years after placement. Once during early adolescence. 5 years.</td>
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<td>What is your first step in management of an asymptomatic [shunted] patient with an increase in ventricle size on a routine scan?</td>
<td>Ophthalmology exam</td>
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<tr>
<td>Ophthalmology evaluation</td>
<td>Eye exam</td>
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<tr>
<td>Ophthalmology exam, check repeat brain image in 2-3 mos</td>
<td>Case specific</td>
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<tr>
<td>It depends</td>
<td>Slight increase -&gt; more frequent F/U; Significant increase -&gt; shunt exploration</td>
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<tr>
<td>Tap or observation depending on degree of change in ventricular size</td>
<td>Adjust valve if programmable otherwise tap</td>
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<td>More frequent observation and consult ophthalmology to rule out papilledema</td>
<td>Repeat MR vent check in 3 months</td>
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<td>If minimal increase 3m f/u, if larger increase shunt series and shunt tap</td>
<td>Eye exam for papilledema, shunt series for fracture</td>
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<td>Dilated eye exam and more frequent observation</td>
<td>Fundoscopic exam</td>
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<td>Eye exam</td>
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<tr>
<th>What is your next step if the shunt series demonstrates an intact shunt?</th>
<th>Ophthalmology evaluation</th>
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<tr>
<td>Papilledema check and close radiographic follow up</td>
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<tr>
<th>What is your next step if the shunt series demonstrates a fractured shunt?</th>
<th>Depends on patient history, age, whether they have ever had a prior shunt failure. Usually first step I will obtain a dilated eye exam to assess for papilledema. Will often discuss shunt exploration and electively revise shunt. Occasionally will observe more frequently.</th>
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<tr>
<td>Myelo - fix always, tumor - almost always fix - premie IVHer with no s/s - either observation or nuc study to see if there is any flow in the tract - if flow, I revise</td>
<td>Ophthalmology exam</td>
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<tr>
<td>Papilledema</td>
<td>Shunt revision for fractured shunt</td>
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<tr>
<th>What is your initial approach to an asymptomatic patient with a fractured shunt catheter on a routine shunt series?</th>
<th>Ophtho exam</th>
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<tr>
<td>Case specific</td>
<td>Myelo - fix always, tumor - almost always fix - premie IVHer with no s/s - either observation or nuc study to see if there is any flow in the tract - if flow, I revise</td>
</tr>
<tr>
<td>More freq observation with MR imaging</td>
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<tr>
<th>What is your next step if the patient's ventricles are stable and the patient is asymptomatic?</th>
<th>Ophtho exam, repeat brain imaging 2-3 mos</th>
</tr>
</thead>
<tbody>
<tr>
<td>If non-myelo patient, then eye exam and watch if no papilledema (revise if papilledema). If myelo patient, much lower threshold to operate, especially if symptomatic with previous shunt failures</td>
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</tbody>
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<tr>
<th>What is your next step if the patient's ventricles are enlarged and the patient is asymptomatic?</th>
<th>Depends a lot on etiology. Will revise SB or PHHP pt. Follow others w freq f/u</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye exam - if papilledema, operate. if not, make judgment of degree of hydrocephalus - if significant (for example, with transependymal edema) operate; if not, then short term (6-12 week) f/u MRI and eye exam.</td>
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<th>After an endoscopic third ventriculostomy, when do you consider the patient's</th>
<th>Variable</th>
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<td>Pretty much immediately. The ventricles typically don't change much in size, and if symptomatic, the symptoms usually resolve immediately.</td>
<td>Depends on age, mechanism, and severity</td>
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<td>Question</td>
<td>Answer</td>
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<tr>
<td>hydrocephalus to have 'stabilized'?</td>
<td>Variable, each patient is assessed individually and clinical/radiographic factors considered. When manifestations for presentation have resolved and imaging shows 3rd ventricle appearance improved (recess collapsed, floor not displaced and lamina terminals not translocated forward. There can be continued improvement in FOHR up to 2 or more years in infants with significant brain growth. Not so for ETV in older patients. I do not do ETVs This depends upon the patients age and clinical status</td>
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<tr>
<td>After reaching 'stability' [following an ETV], how often do you ask a patient to return for routine clinical follow-up?</td>
<td>After 21 years of age No follow from surgery unless they have signs/symptoms Transition to adult care between 18 and 21. Same answer as above I do not do ETVs Don’t know the answer - given cases of late failure</td>
</tr>
<tr>
<td>How frequently is a head CT obtained [following an ETV]?</td>
<td>5 years For stable asymptomatic patients I get a CT or MRI every five years One year after the surgery and then every two years thereafter.</td>
</tr>
<tr>
<td>How frequently is a brain MRI obtained [following an ETV]?</td>
<td>One time at 3 months postop q 5 years Once a year for a couple years, then less frequently 5 years 5 years Limited Sequence MRI at 6 weeks, then 3 months and 6 months following surgery, then every 12 months For stable asymptomatic patients I get a CT or MRI every five years 6-12 weeks post-op. Additional future studies may be obtained if robust flow jet extending to foramen is not visible Every 5 y More frequent initially then space out, 1 year, then 2 years, then 5 years, etc. Often we will do 6 months after surgery to confirm patency, then stop doing imaging Asymptomatic baseline, typically about a year after ETV It depends 6 months, 1 year, q2-5 years thereafter 6 months later for steady-state I image tectal gliomas yearly x 2, then q2yrs. For other indications, only image for symptoms Depends on age and how far out from ETV One at 1 year, then at 2 years, then at 5 years, and then only if new symptoms 3 months and 1 year post op then prn for symptoms Family wants a picture, complex ventricular anatomy. 5 years One year after the surgery and then every two years thereafter. At 1 year post ETV, 3 years, 5 years, 10 years If there has been no scan in prior 5 years</td>
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<td><strong>Annually for 5 or less years old, every two or three years as they get older</strong></td>
<td><strong>Within first 5y post yearly, after 5y stability q2y</strong></td>
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<tr>
<td><strong>Up to date to within 5 years</strong></td>
<td><strong>4-5 years</strong></td>
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<td><strong>Several years</strong></td>
<td><strong>The frequency of surveillance increases with the length of time the patient remains without symptoms</strong></td>
</tr>
<tr>
<td><strong>5 scans across childhood</strong></td>
<td><strong>Up to date to within 5 years</strong></td>
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**How do you manage an asymptomatic patient with an increase in ventricle size on a routine scan (following an ETV)?**

- Ophtho exam
- Ophthalmology evaluation
- Ophthalmology evaluation
- Ophtho exam, repeat imaging
- Case specific

  - Dilated eye exam and more frequent observation and surveillance imaging.
  - It depends
  - Ophthalmology and more frequently observations
  - If they are shunted, would do a shunt flow study.

  - Ophtho eval, more frequent observation, imaging to assess patency of ETV (T2 space, bFFE, CISS, etc.)
  - Clinical examination first, then re-exploration
  - I offer family the option of endo exploration vs close observation

  - More frequent observation and consult with ophthalmology to rule out papilledema
  - Evaluate the FOHR
  - Repeat scan in 3 months

  - I do not do ETVs
  - Fundoscopic examination

  - Consider more detailed MRI or ICP monitoring
  - Ophthalmology exam, MRI CSF flow studies

  - Would obtain CSF flow study
  - Eye exam