**ABO IMPROVEMENT IN MEDICAL PRACTICE ACTIVITY**

**(CLINICAL)**

**Topic**

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| **Title of Project**: | Improvement in Guideline-Concordant Surveillance Imaging in Patients with von Hippel-Lindau Syndrome |

**Project Description**

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| Describe the quality gap or issued addressed by this activity. (Included in your response to this question should be a description of the resources that informed your decision to pursue this topic, a description of what the literature says about the issue you identified, and the rationale for choosing to address this clinical project | Patients with von Hippel-Lindau (VHL) syndrome present to ophthalmologists because of the high prevalence of retinal capillary hemangioma (RCH). In addition to making the diagnosis of VHL, the appropriate management of a patient with newly-diagnosed VHL includes referral for appropriate systemic imaging to rule out other associated malignant and benign tumors. Because many subspecialists are involved in caring for the protean manifestations of this syndrome, care is often fragmented. In addition, primary care physicians are often unaware of the surveillance guidelines for this rare disease. Appropriate surveillance can be life-saving but is often neglected due to fragmentation of care. |
| **Background Information**:  The month you pulled the baseline IRIS performance report and any additional information that me be pertinent: | Because of the many subspecialists involved, it is critical that one individual take responsibility for coordinating the lifelong surveillance imaging required by these patients. While primary care physicians are often called on to fill this role, many are not familiar with the published guidelines, since this is a relatively rare entity. In addition, the ophthalmologist must not assume that a referring specialist in another field has assumed responsibility for this imaging. At the same time, it is often not within the scope of most ophthalmologists to manage life-long surveillance imaging, which might include MRI imaging of the CNS, abdominal ultrasounds, serum metanephrine level testing, and various other studies, each performed at their own indicated interval. Our intervention was to create a VHL Comprehensive Clinical Care Center (CCCC) at Vanderbilt. For each involved subspecialty (ophthalmology, neurosurgery, urology, neuro-otology, endocrinology, etc.), a single physician would be designated to assume the care of these complex patients in that field. In addition, a single medical oncologist (for adult patients, with a pediatric oncologist counterpart managing children with the disease) would assume responsibility for the global management of these patients, including surveillance imaging. This should simplify the process for all referring subspecialists and thus increase the rate of guideline-concordant screening, which has been shown to improve VHL patient survival. As a member of the newly-formed Vanderbilt VHL comprehensive clinical care center, I examine all patients with VHL or retinal capillary hemangioma at Vanderbilt. In addition, as a retina specialist and ocular oncologist, I am referred all patients from outside Vanderbilt with presumed retinal capillary hemangioma, or who have a family history or new diagnosis of VHL. Most of these patients arrive having never had appropriate screening imaging. |
| **Project Setting**: (Please select from options below):   * Group Practice * Healthcare Network * Hospital * Multi-Specialty Group * Solo Practice * Surgical Center * Other | Hospital |
| **Study population**:  (describe the type of patient for whom the care process will be improved, e.g., all patients in your practice, patients with diabetes, patients presenting for emergency care: | Patients referred to my practice for evaluation of presumed retinal capillary hemangioma, or with a diagnosis of VHL. |
| **Quality Indicators / Performance Measures**:  It is important to carefully define outcome or performance measures that will be quantified at baseline (before the care process is changed) and at re-measurement (after you have implemented the proposed improvement) to quantify the impact of your care process change. There are two basic types of performance measures - process of care measures and outcomes of care measures.  . Process of care measures (e.g. timely treatment of diabetic retinopathy) can influence outcome measure (e.g. decreased risk of severe vision loss);  . Outcome measures can be linked to processes of care that can be improved.  Generally, performance measures are expressed as rates, often as percentage rates. For example, if the intent of a project is to improve the quality of glaucoma care in your practice, you may choose to improve your rate of establishing a goal IOP in patients with newly diagnosed glaucoma, measured over a 3-month period.  . The numerator of this process measure would be the number of newly diagnosed patients during this time who have a goal IOP recorded in the medical record.  . The denominator would be the total number of patients diagnosed during that same time period.  Continuous variables (e.g. the refracted spherical equivalent after cataract surgery) can often be simplified and transformed then into percentage rates  by setting a quality threshold (within 0.5 diopters in the intended spherical equivalent) which, if attained, would qualify the patient to be in the numerator (e.g. number of patients within 0.5 diopters / total number of patients). It can be advantageous but not mandatory to have more than one quality measure in order to gauge the impact of your process change. In the example above, an additional outcome measure might be the percentage of patients in whom the goal IOP is attained within the first 6 months after diagnosis.  If possible, measure quality indicators for at least 30 individual patients or data points during the baseline and again during the follow up period. | * **Measure Type:** Process * **Measure Name:** Guideline-concordant systemic surveillance imaging * **Numerator Statement:** Number of VHL patients who are up to date on guideline-concordant imaging by 6 months following ophthalmic evaluation by me. * **Denominator Statement:** VHL patients presenting for ophthalmic evaluation by me. |
| We realize that this may not be feasible or appropriate for all projects. Please indicate at least one measure below; either a process or outcome measure:  **Example Measure**:  . **Measure Type**: Process Measure  . **Measure Name**: Patient pain level during intravitreal injection  . **Numerator Statement**: Number of patients in who pain levels decreased by 2 points on a 1-10 scale  . **Denominator Statement**: 30 consecutive patients undergoing intravitreal injection. |  |
| **Project Interventions**:  Quality improvement requires that you analyze your care delivery processes and identify changes, which if implemented, will improve care and outcomes. Generally, educational interventions are thought to be weak and demonstrate little impact. The introduction of tools, strategies or systematic approaches to care delivery is more powerful. A tool is a thing, for example a preoperative checklist, or written standardized process or protocol. Strategies include changes in procedures or policies like the introduction of a surgical time out before surgery is initiated. Systematic approaches to care delivery involve a comprehensive analysis of care process and the introduction of a combination of tools and strategies designed as a complete process. Please describe the changes to your care processes you intend to introduce: | Historically, I referred patients with VHL to their primary care physicians for systemic surveillance imaging or attempted to determine if the referring physician had instituted a care plan for surveillance imaging. The intervention was the routine referral of all patients to the VHL comprehensive clinical care center's designated adult or pediatric oncologist for coordination of care, regardless of any prior testing that had been ordered by any of the doctors who had initially referred the patient to me, or by the patient's primary care physician. |
| **Project Team**:  (include roles for yourself and all members of your team):  List the individuals who will be involved in your quality improvement project (i.e., solo project, partners in practice, office staff, OR personnel, anesthesiologists) and the roles they will contribute. | **Me**: Evaluate patients, diagnose retinal capillary hemangioma/VHL, make refer to VHL comprehensive clinical care center oncologist. Oversee QI project design, data collection, and all research activities related to this project. **Nurse clinical coordinator**: Will contact VHL comprehensive clinical care center oncologist and coordinate an initial visit for the patient with the clinic. **VHL comprehensive clinical care center oncologist**: Will be the one to order the guideline-appropriate surveillance imaging. **Ophthalmology resident**: Will track rates of guideline-concordant imaging as of 6 months following presentation to my clinic for evaluation. |
| Will any other ophthalmologists be requesting MOC credit for participation in this SD-PIM? | No |

**Project Outcomes/Results**

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| **Project Summary** | In the following sections, please prepare a brief summary of the project highlighting the data collected, effectiveness of your measurement approach, interventions, and the overall impact of the project. |
| **Baseline Data**:  Quantify each of the quality indicators / performance measures described above for the baseline period (before interventions for improvement were introduced). Report the numerator, denominator and the calculated percentage rate for each measure. | Performance measure: guideline-concordant surveillance imaging. During the pre-intervention time period, 7 patients met inclusion criteria. 0/7 patients (0%) were already guideline concordant before seeing me, and only 2/7 (29%) were guideline concordant within 6 months after my evaluation of the patient. The rate of increase in guideline concordance for patients presenting to my clinic was 29%, in the time period prior to the process improvement initiative. |
| **Follow-up Data**:  Quantify each of the quality indicators / performance measures described above for the re-measurement period (the period following implementation of the interventions for improvement). | During the post-intervention time period, 10 patients met inclusion criteria.  A process measure I tracked was the rate of referral to the VHL Comprehensive Clinical Care Center (CCCC) Oncologist. 100% of patients (10/10) were successfully referred to the VHL CCCC Oncologist.  Performance measure: guideline-concordant surveillance imaging  2/10 patients (20%) were already guideline concordant before seeing me, and all 10/10 (100%) were guideline concordant within 6 months after my evaluation of the patient, and referral to the Oncologist. The rate of increase in guideline concordance for patients presenting to my clinic was 80%, in the time period following to the process  improvement initiative. |

**Project Impact**

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| Compare the baseline data to the re-measurement / follow-up data and quantify the impact of the process of care changes (your project interventions). The project hopefully resulted in improvement; however, some projects may result in a diminution in quality. If a lack of improvement or reduction in quality occurred, suggest other strategies that might be more effective. | We found that BASELINE rates of guideline-concordant surveillance imaging were very low for patients at the time that they presented to my clinic, both in the pre-intervention group as well as in the post intervention group. During the pre-intervention time period, I was doing a very poor job of increasing rates of guideline-concordant surveillance imaging. In a post hoc subgroup analysis, during the pre-intervention period, the only patients who became guideline concordant within 6 months of seeing me were those patients who only required the eye examination I provided in order to become concordant. In other words, for the remainder of patients, I was not ensuring that that any of them became up to date in their systemic surveillance after seeing me. In contrast, in the post-intervention time period, all patients were referred to Oncology, and all patients became concordant with surveillance guidelines.  The quantified improvement was 71% (29% pre-intervention and 100% post-intervention). Importantly, this process improvement project led to 100% concordance with published imaging guidelines (which is almost unheard of in the VHL field). Surveillance imaging has been shown to lead to earlier detection of tumors associated with VHL syndrome. In designing this project, I had assumed that an improvement in rates of detection of tumors would take decades to demonstrate directly, and so I was using guideline-concordant imaging as a surrogate endpoint. Shockingly, we found that 50% of patients referred for surveillance imaging had a (non-ocular) tumor large enough to require some intervention at the time of the initial imaging to make them concordant. These included renal cell carcinomas (>3cm), pheochromocytomas, pancreatic tumors, metastatic rhabdoid tumors, and central nervous system hemangioblastomas. Thus, the ultimate impact of improving detection of tumors in VHL patients could actually be demonstrated over the short time period of this project. This number is frightening, because of its implications for ophthalmologists screening patients with VHL. Of all the patients being sent out without ensuring that appropriate surveillance imaging is arranged, 50% of all those patients will have a (non-ocular, and potentially life-threatening) tumor that has been missed.  The results of this quality improvement project were presented at the recent Biennial International VHL Research Symposium. Because of the profound findings of this admittedly small pilot project, we are embarking on a multi-institutional study to determine if this process improvement strategy can be generalized, and if the rates of undetected systemic tumors among VHL patients presenting to ophthalmologists can be validated. The multi-institutional study which is just beginning to recruit sites, will be named the "VHL Improved surveillance Imaging Concordance Through Ophthalmology Reflex Referral to oncology" (VICTORY) Study. |

**Project Reflection**

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| Did you feel the project was worthwhile, effective? | Yes |
| How might you have performed the project differently? | I think that the approach that I took worked quite well, overall. Alternative approaches, such as relying on patient questionnaires, who likely have been less effective, due to recall bias and also the fact that patients may have been unclear as to exactly what was being imaged during a previous body scan (e.g., don't know if the MRI they had last year was of the CNS only or also of the abdomen). |
| Please offer suggestions for other ophthalmologists undertaking a similar project. | It is important to ensure that you are being very consistent about what qualifies as "guideline-concordant". |