Universal Reflex Referral to VHL Comprehensive Clinical Care
Center of Patients Presenting to Ophthalmologists Leads to
Dramatic Improvement in Guideline-concordant Screening:
Results of a Pilot Study

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Case Study

• 16 year old male
• Diagnosed with VHL at age 9
• Known cerebellar hemangioblastoma, RCH

Case Study

• Referred for ophthalmic examination
• Prior ophthalmologist had relocated
• Hadn’t seen ophthalmology in 2 years
Case Study

• Followed by:
  – Pediatrician
  – Geneticist
  – Retina Specialist (Ophthalmology)
  – Neurosurgeon
  – Neuro-oncologist

Case Study

• Surveillance Imaging:
  – “Gets MRI of my whole body 1-2 times per year”

Tumors in VHL

Surveillance Guidelines for VHL
Sounds pretty good...

Case Study

- MRI Brain and spine:

- Had never had:
  - abdominal MRI
  - (or metanephrines, audiometry)

Case Study

- Subsequent MRI showed a lesion in the kidney
- Ended up having metastatic rhabdoid tumor
How was a child with known VHL, followed by so many specialists, allowed to present with cancer that had already metastasized?

Rationale

• VHL patients see many specialists
• Care may be fragmented
• Specialists focus on their own organ, not necessarily the whole patient
• Assumption that “somebody else” is managing the surveillance imaging

Quality Improvement Project

Rationale

• VHL patients see many specialists
• Ophthalmologists might not know who is following what

Endocrine  Meta-nephrines
Neurosurg  CNS MRI
Audiology  Audiology
Renal/Onc  Abdominal Imaging
Rationale
• Ophthalmologists are often first to identify VHL

Intervention
• Referral of all VHL patients to CCCC oncologist to monitor surveillance imaging
  – Regardless of which other specialists were monitoring other specific organ systems

Rationale
• Ophthalmologists are often first to identify VHL
• Not set up to manage/follow-up systemic testing

Intervention
• Referral of all VHL patients to CCCC oncologist to monitor surveillance imaging
  – Regardless of which other specialists were monitoring other specific organ systems
Patients Included

- All patients presenting to ophthalmology at VUMC with a new or established VHL diagnosis
Patients Excluded

• Patients referred to ophthalmology BY VUMC’s CCCC oncologist

Patients Excluded

• Patients referred to both ophthalmology AND VUMC’s CCCC oncologist, but had not seen oncology? Appt with oncology was confirmed.

Patients Excluded

• Patients referred to ophthalmology BY VUMC’s CCCC oncologist

VHL CCCC at Vanderbilt

• VUMC became a CCCC in 2017
Comparison Groups

- Pre-intervention group compared to post-intervention group
  - Roughly:
    - mid-2016 to mid-2017
    - vs.
    - mid-2017 to mid-2018

Process Measure

- Rate of referral to oncology (or confirming appt)

Outcome Measure

- Rate of surveillance guideline-concordance after seeing ophthalmology/oncology

Clinical Impact

- Fraction of patients in whom a tumor is found
Clinical Impact

• Fraction of patients in whom a tumor is found

Results

• 12 patients were excluded from analysis
  – had already seen the CCC Oncologist
Results: Patients

• 12 patients were excluded from analysis
• 5 patients declined appt with CCCC oncologist
  – Lived very far away
  – Already had local oncologist managing surveillance
  – Veteran’s Affairs system patients
• 7 patients before instituting universal referral
  – “pre-intervention group”
  – mid-2016 to mid-2017
• 10 patients after instituting universal referral
  – “post-intervention group”
  – mid-2017 to mid-2018

Results: Process Measure

• 100% of patients seen by ophthalmology were referred to CCCC oncologist

Results: Outcome Measure

All Patients
Results: Clinical Impact

• 50% of patients referred for surveillance were found to have a tumor requiring action on the initial testing by the CCCC oncologist.

• These included renal cell carcinomas (>3cm), pheochromocytomas, pancreatic tumors, metastatic rhabdoid tumors, and central nervous system hemangioblastomas.
Results: Clinical Impact

- These included renal cell carcinomas (>3cm), pheochromocytomas, pancreatic tumors, metastatic rhabdoid tumors, and central nervous system hemangioblastomas

Conclusions

- Simple intervention: Refer ALL pts to oncologist
- **Dramatic improvement** in guideline-concordance
  - From 0% to 100%
- **HALF of all patients** seeing ophthalmology had another tumor – and didn’t know it!

Conclusions

- Simple intervention: Refer ALL pts to oncologist
- **Dramatic improvement** in guideline-concordance
  - From 0% to 100%
- **HALF of all patients** seeing ophthalmology had another tumor – and didn’t know it!

- For any specialist seeing a patient with VHL, think about what other cancers you are sending out the door...

Multi-Institutional Clinical Trial
Multi-Institutional Clinical Trial

“VHL Improved surveillance Imaging Concordance Through Ophthalmology Reflex Referral to oncology”

The VICTORY Trial

• Open to all CCCs / CCCCs
• Contact me if you are interested in participating

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Thank You!

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