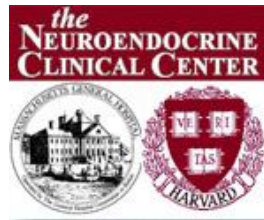


# Pituitary Tumor Centers of Excellence

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October 4, 2019



# Question

Have you ever encountered any difficulties making an appointment with the doctor of your choice or having pituitary surgery at the hospital of your choice for any reason (e.g. insurance denial, reluctance of referring physician):

- Yes
- No

# Pituitary Tumor Centers of Excellence (PTCOE)

- The concept of the (proposed) PTCOE
- Patient outcomes in relation to surgical expertise
- Proposed criteria for the definition and characteristics of PTCOE (Pituitary Society)
- Summary

# What is the proposed definition and characteristics of the PTCOE?

- Multidisciplinary centers designed to provide the best possible care for patients with pituitary tumors or related pathologies (including Cushing's disease)
- Providing patient education and community outreach
- Acting as training centers for residents and other health professionals
- Aimed at advancing pituitary science
- Recognized by neurosurgical and endocrine professional organizations
- Centers accredited and periodically audited

Currently, no formal accreditation for PTCOE exists

Adapted from Casanueva et al,  
Pituitary, 2017

# Patient outcomes in relation to surgical expertise

Progressive improvement in outcomes of patients undergoing pituitary surgery during Cushing's career:

- Mortality rate: 40% (multiple early surgeons before Harvey Cushing)
- Mortality rate: 13.7% (Harvey Cushing's early series; Cushing H, 1912)
- Mortality rate: 3.9% (close to the end of Harvey Cushing's career; Cushing H, 1932)

# Outcomes of patients with Cushing's disease undergoing pituitary surgery in relation to surgical expertise

	<i>n</i>	Surgery	Remission		Extrasellar (%)	Hypopituitarism (%)	Complications (%)
			Total (%)	Intrasellar (%)			
Surgeon A (1980–89) (10)*	15	T 12 H 2 S 1	67	69	50	87	13
Surgeon B (1990–97) (5–10)*	21	T 9 H 8 S 4	86	89	67	48	19
Surgeon C (1995–2000) (30)*	17	T 3 H 5 S 9	76	100	20†	29	12

T, total hypophysectomy; H, hemihypophysectomy; S, selective adenomectomy. \*Figures represent average number of total pituitary operations per year (all conditions). †Three out of five were large tumours extending into the cavernous sinus and referred specifically to surgeon C in his capacity as a neurosurgeon.

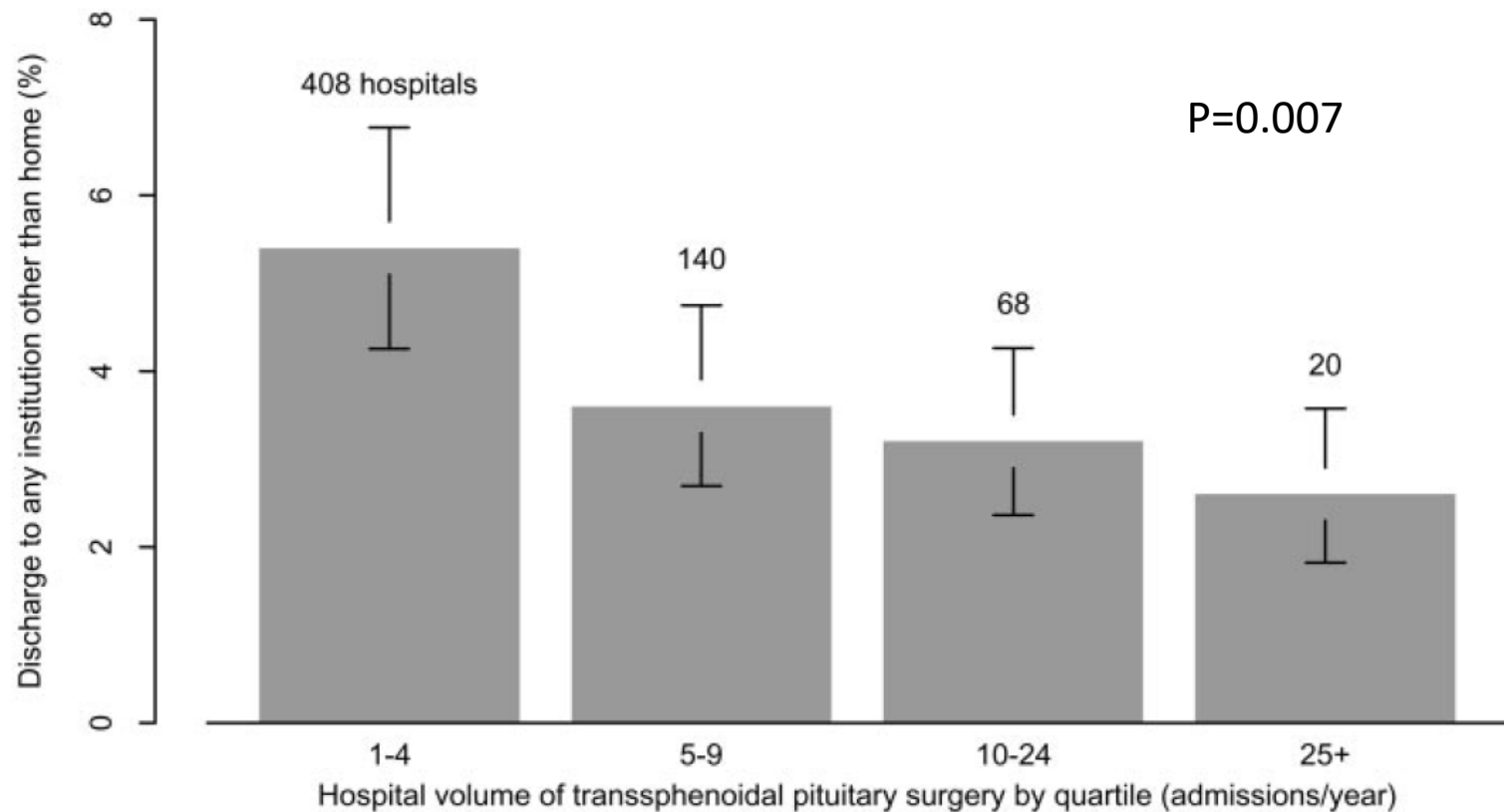
# Outcomes of patients undergoing pituitary surgery in relation to surgeons' expertise

- Data were analyzed from the Nationwide Inpatient Sample (NIS) between 1996-2000
- Information on approximately 20% of pituitary operations in non-federal hospitals in the US
- Study aimed at examining patient outcomes (disposition at discharge, in-hospital mortality, complications, hospital charges) in relation to hospital and surgeon case load

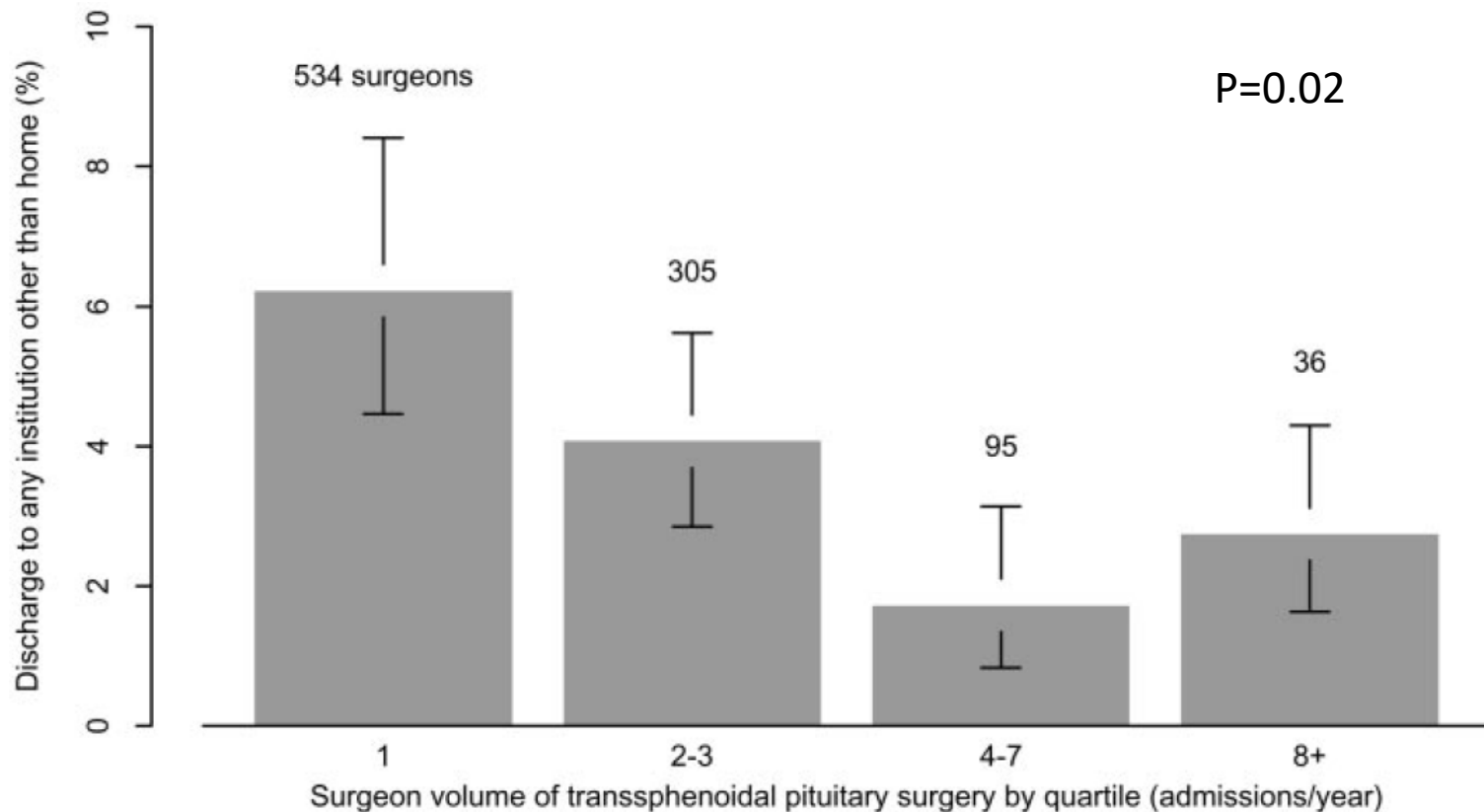
# Patient characteristics

Patient characteristics	
Number of patients	5497
Age (median), (range)	49 yr, (0-91 yr)
Female (%)	2935 (53%)
Procedure	
Biopsy	45 (0.8%)
Partial hypophysectomy	4091 (74%)
Total hypophysectomy	1361 (25%)
Cushing's disease	383 (7%)
Acromegaly	312 (6%)
Number of hospitals	538
In-hospital mortality	32 (0.6%)
Discharge other than to home	170 (3.1%)
Complication rate (%)	1457 (26.5%)

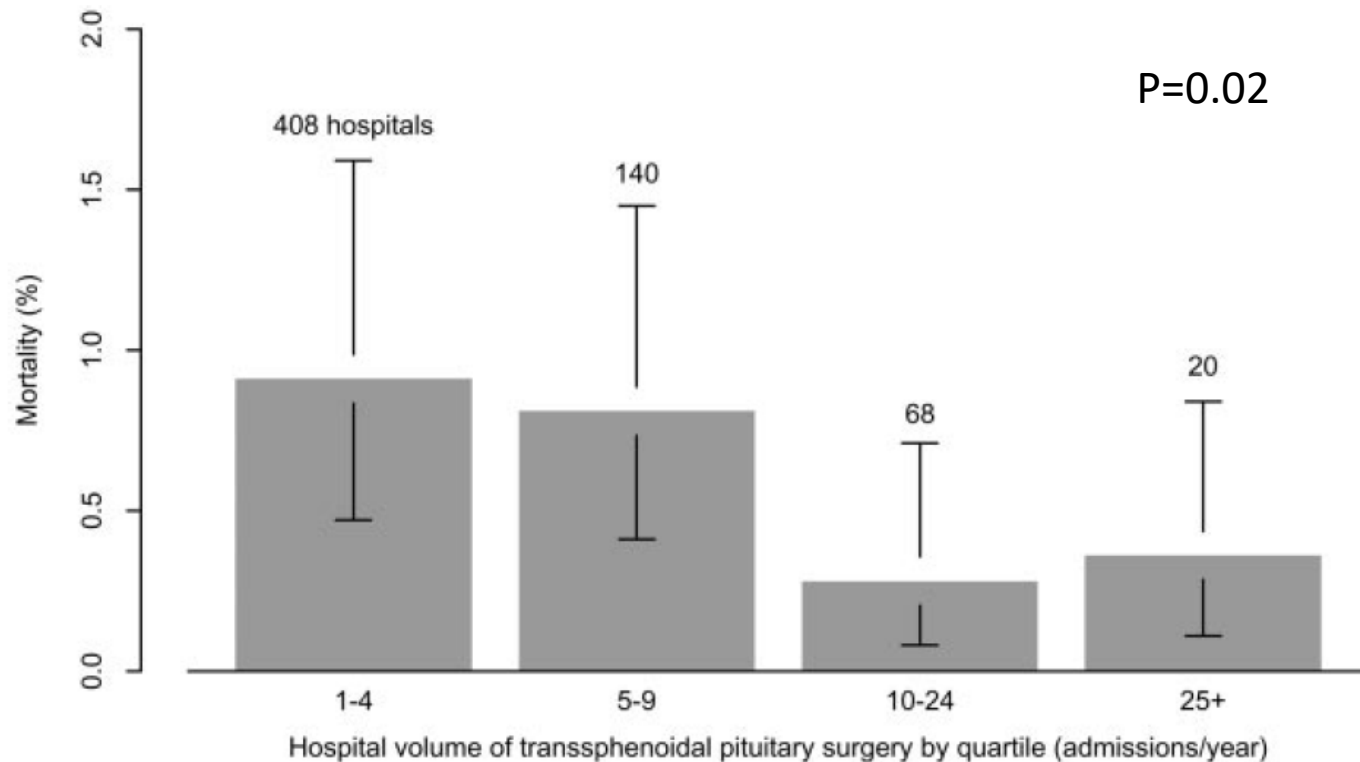
# Probability of discharge other than to home after pituitary surgery



# Probability of discharge other than to home after pituitary surgery

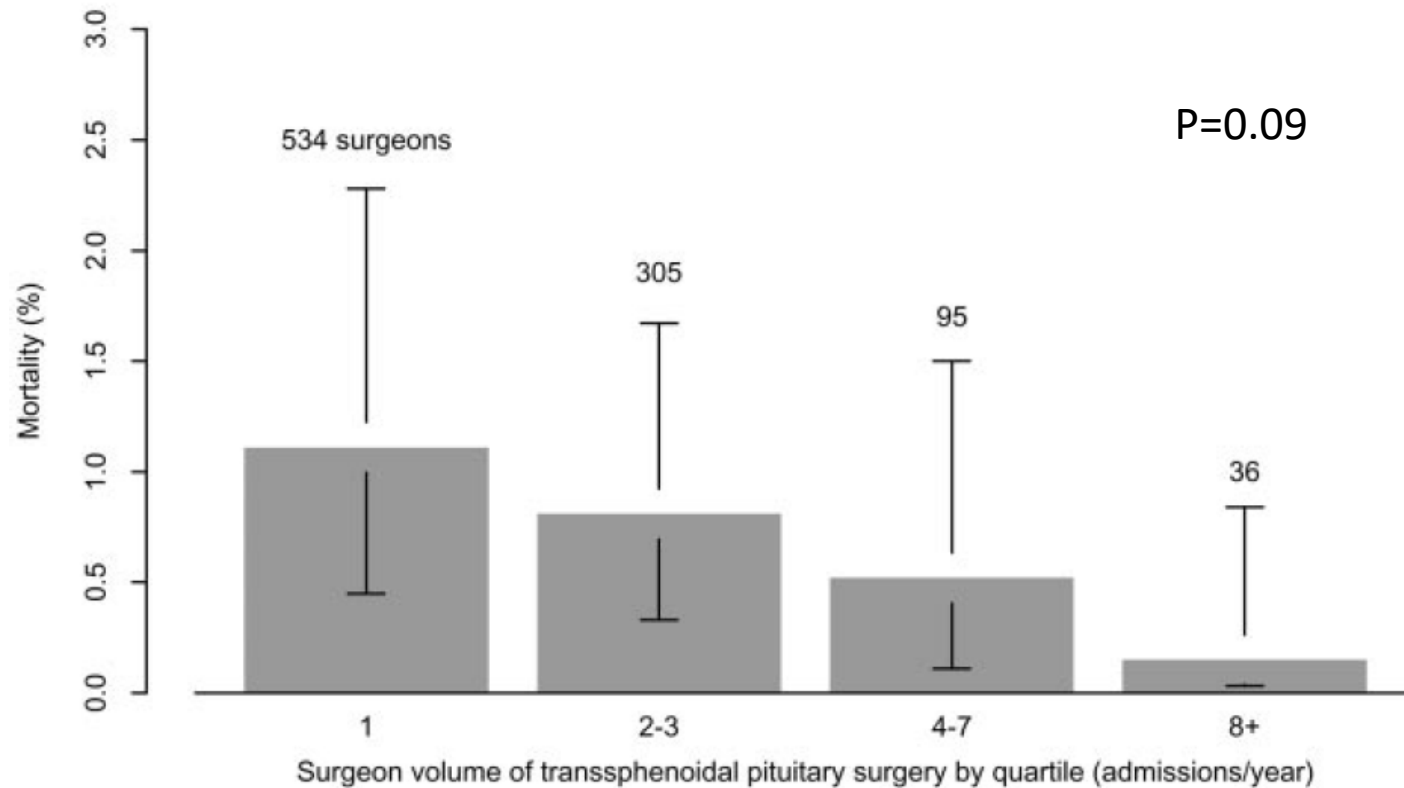


# Probability of in-hospital mortality after pituitary surgery



Barker et al, JCEM, 2003

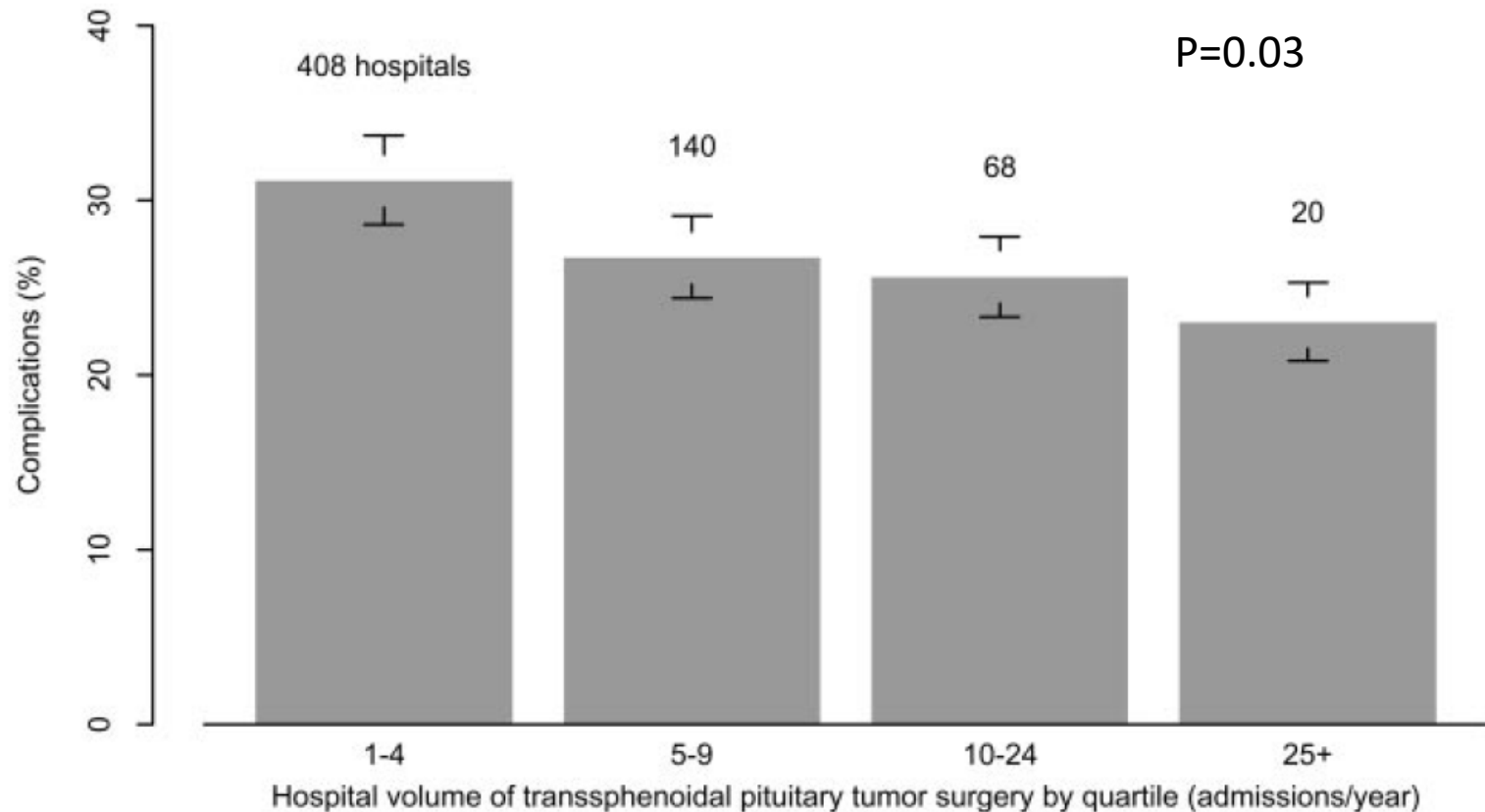
# Probability of in-hospital mortality after pituitary surgery



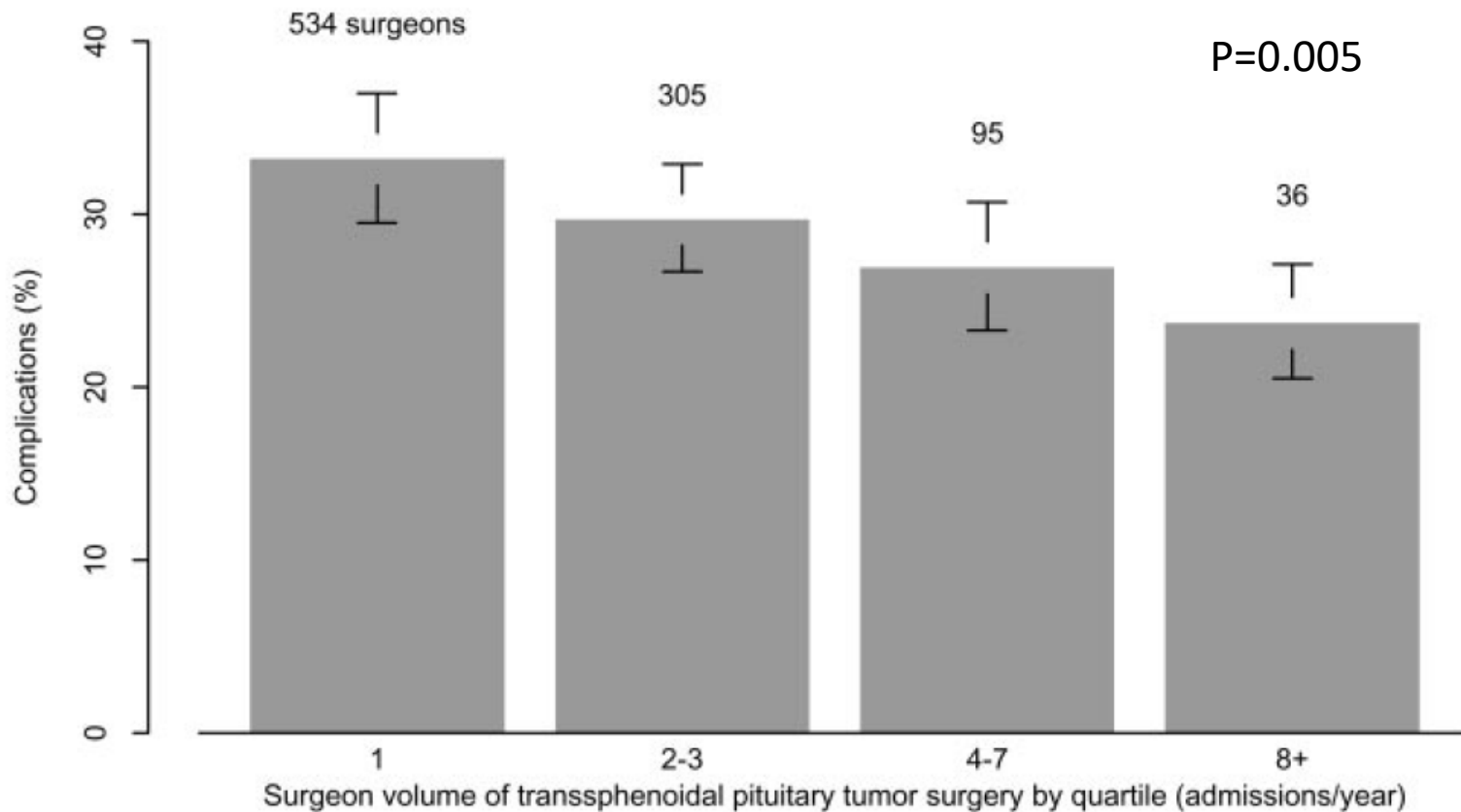
# Complications after pituitary surgery

Complication	N=5497
Infarction or hemorrhage	254 (4.6%)
Hematoma	86 (1.6%)
Any intracranial hemorrhage	126 (2.3%)
Fluid and electrolyte abnormalities	486 (8.8%)
Diabetes insipidus	578 (10.5%)
Hypopituitarism (iatrogenic)	46 (0.8%)
Cerebrospinal fluid rhinorrhea (CSF leak)	77 (1.4%)
Cranial nerve (3, 4, 6) palsies	176 (3.2%)
Vein clot formation (deep venous thrombosis or pulmonary embolism)	31 (0.6%)

# Probability of one or more complications after pituitary surgery



# Probability of one or more complications after pituitary surgery



# Length of stay and hospital charges

- Length of stay (LOS) decreased by 4.6% per year between 1996-2000 ( $P<0.001$ )
- Median LOS was 4 days throughout the study period
- LOS was shorter at larger-volume hospitals ( $P=0.02$ ) and was shorter among surgeons with larger caseloads ( $P<0.001$ )
- Total hospital charges increased from (median) of \$17,100 in 1996 to \$20,200 in 2000 ( $P=0.02$ )
- Charges tended to be lower (by 7.6%) at higher volume hospitals ( $P=0.2$ )

# Proposed criteria for the definition of Pituitary Tumor Centers of Excellence

- A task force of experts from the Pituitary Society drafted a set of proposed criteria for defining the mission and characteristics of PTCOE
- These were debated by the membership and approved by the Board of Directors
- A document detailing these criteria was endorsed by the membership and was published in 2017

# Proposed mission of the PTCOE

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1. Provide the best standard of care to patients with pituitary tumors and disorders
  2. Organize multidisciplinary clinical management
  3. Liaison between experienced neurosurgeons and expert neuroendocrinologists
  4. Work with the supporting specialties
  5. Train fellows in the management of pituitary tumors and related disorders
  6. Provide courses, publications and lectures for primary care physicians and other specialists
  7. Capture and track clinical data
  8. Provide up to date and comprehensive patient information
  9. Present results and outcomes to scientific bodies and administrators
  10. Support endocrine units located outside the PTCOE
  11. Advise health administrators and authorities on specific problems
  12. Advance the science and scholarship of pituitary tumors
  13. Include tumor data on National or Regional registries

# Proposed requirements for neurosurgeons practicing in PTCOE

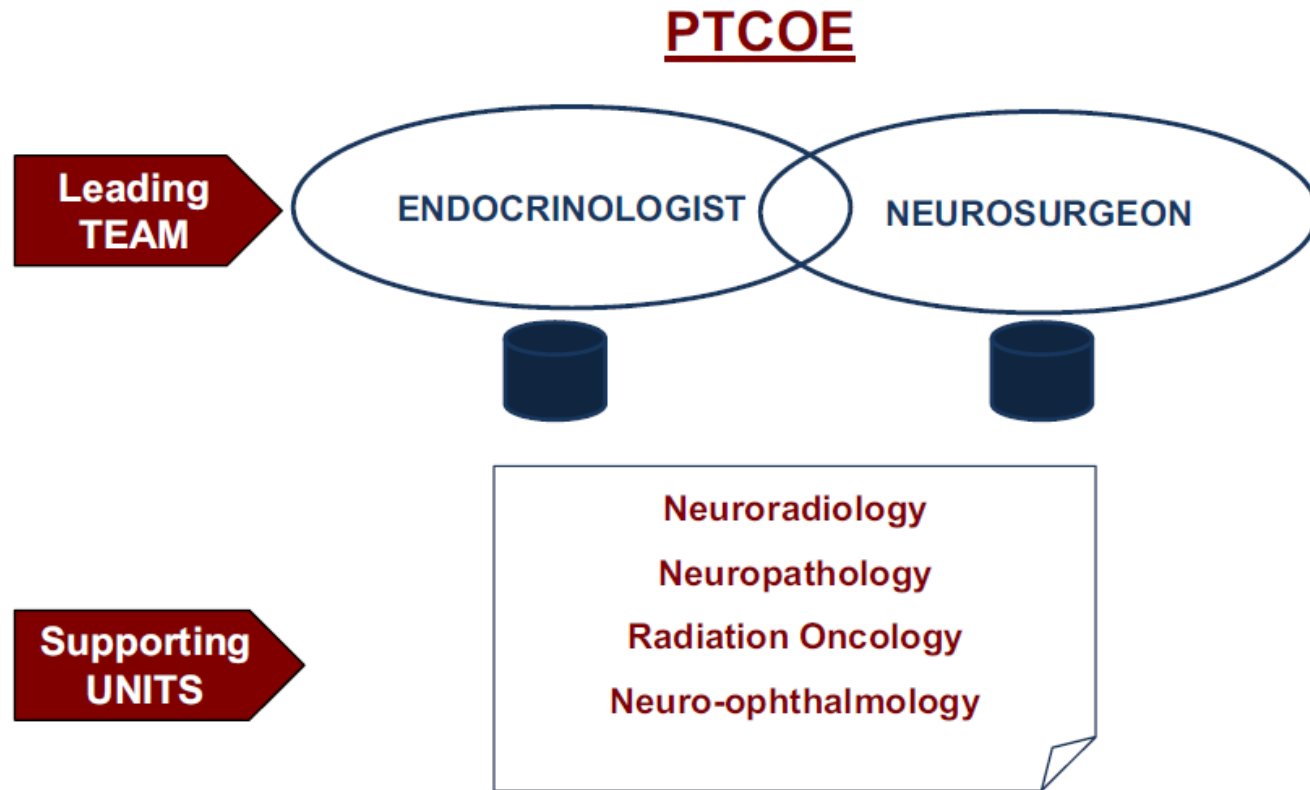
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1. Basic residency training in neurosurgery at an accredited center
  2. Post-residency fellowship (12–15 months) in an active, high-level pituitary surgery unit, or extensive training in pituitary surgery and pituitary patient management at an established pituitary center
  3. Continuous practice in a newly created or previously recognized unit with a high pituitary workload and demonstrated outcomes
  4. Contribute to the advancement of Pituitary Science through publications in medical journals, chapters in books and monographics
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# Proposed requirements for endocrinologists practicing in PTCOE

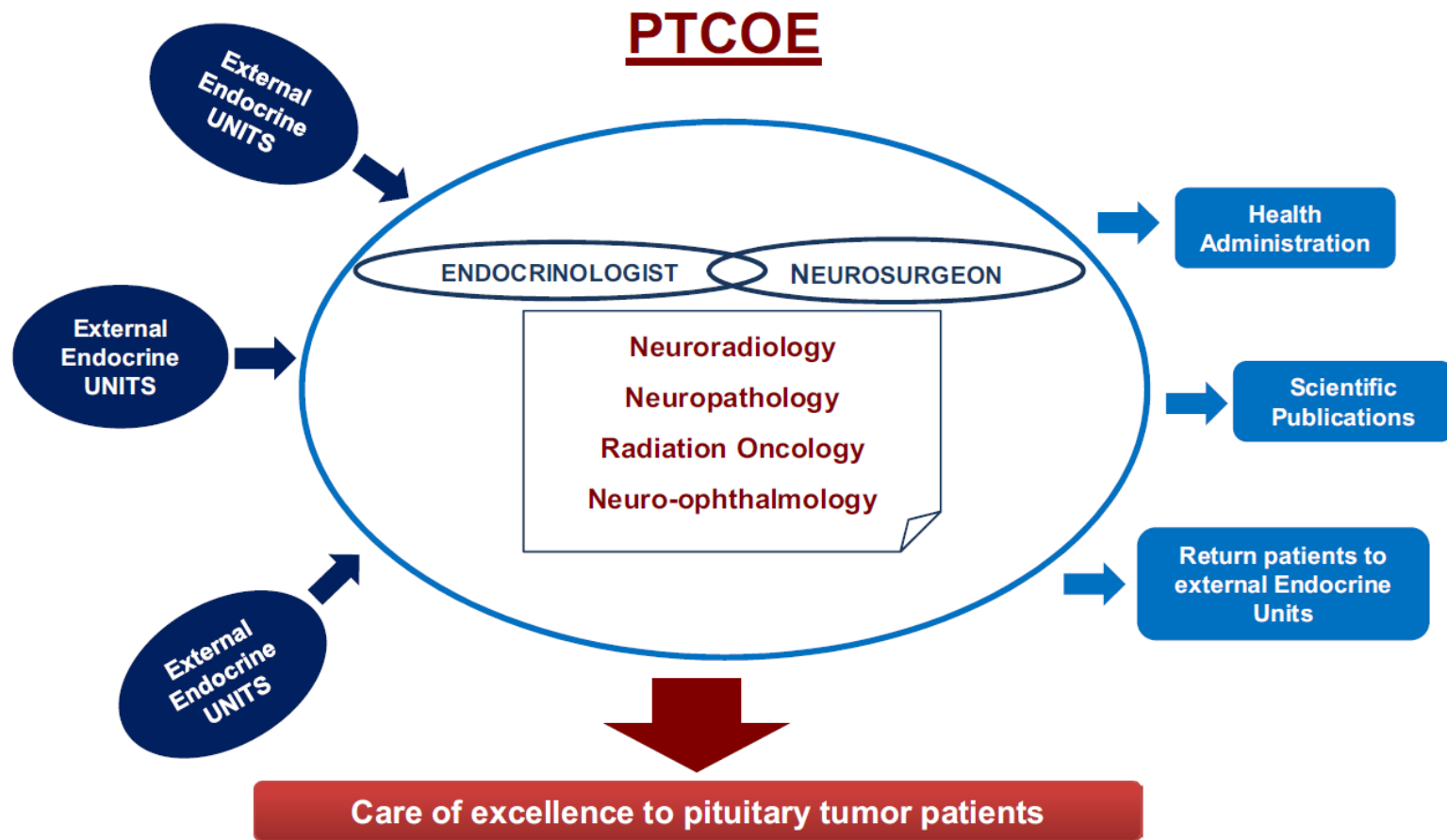
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1. Specialty medical training in internal medicine or adequate alternatives and in endocrinology
  2. Postgraduate training at a center with a unit dedicated to pituitary disorders
  3. Working at a PTCOE with intense activity and a high workload
  4. Presenting results at scientific events and to health administration bodies
  5. Contributions to the advancement of pituitary science, and discovery in pituitary medicine
-

# Proposed structure of the PTCOE



# Proposed work flow in the PTCOE



# Summary

- Clinical outcomes are improved when patients undergo pituitary surgery by more experienced neurosurgeons operating at higher volume centers
- The Pituitary Society has proposed criteria for the Pituitary Tumor Centers of Excellence (however, no formal accreditation mechanisms for PTCOE currently exist)
- The establishment of accredited and audited PTCOE has the potential to further improve clinical outcomes for patients with pituitary tumors (including Cushing's disease)

# What to do when the closest Pituitary Center is far away

Adriana Ioachimescu, MD, PhD

October 4, 2019



# Locating a Pituitary Center

- Resources
  - Local endocrinologist or neurosurgeon
  - Patient support organizations
  - Google search: pituitary center + state
    - PTCOE website
- Where is the patient in the Cushing's journey

# *The experience with transsphenoidal surgery and its importance to outcomes*

Honegger J, Pituitary, 2018

- All surgical series since 1990 reviewed (59 publications, 5,207 patients)
- Remission rates >85% only reported for single surgeon series
- Correlation found between early remission and the number of operations for Cushing's disease

# Other reasons to visit a PTCOE

- Dedicated pituitary endocrinologists
  - Evaluate a large number of patients with rare diseases
  - Offer 2<sup>nd</sup> opinions for challenging cases
  - Have experience with medications that are not frequently used by the general endocrinologist
- Multidisciplinary care
  - Tertiary and quaternary referral centers
- Research activities
  - Capture & track internal outcomes
  - Clinical trials
  - Investigator-initiated research
  - Publications
- Educational activities for healthcare professionals and patients

# Patient-centered care



# Local endocrinologists

- Communicate with the specialists at the PTCOE
- Evaluate patients in-between PTCOE visits
- Manage blood pressure, glucose and other medical issues
- Remain involved in patient's care, while the PTCOE delivers highly specialized services and expert advice

# Local laboratory

- Salivary cortisol kits can be mailed
- Some experience in hormone measurement is needed
- Things to ask:
  - What is the turnaround time for results
  - Will the patient be able to access the results directly
  - Will the results be sent to the PTCOE or to the local physician
  - Phone #

# Local imaging center

- After the scan was completed, patients can request the images to be loaded on a disc which can be...
  - Mailed to the PTCOE
  - Used for comparison when MRI is repeated elsewhere
- Protocols used for pituitary MRI evaluation are not standardized
  - Visualization of small lesions requires use of modern MRI protocols
  - Check in advance with PTCOE team and the insurance company

# If surgery done elsewhere...

- Protocols differ from center to center
- Medical records are essential
  - Operative notes
  - Anatomic-pathology reports
  - Laboratory results
  - Imaging reports

# Neuropathology standards



The PTCOE team may request the tumor specimen or slides for additional staining and evaluation

# Before the PTCOE visit

A white rectangular card with a black header that reads "To Do list:". Below the header is a table with two columns: "TASK" and "DONE". The "TASK" column contains ten horizontal lines for writing. The "DONE" column contains ten small square checkboxes. The card is set against a light orange background.

# Instead of conclusions

- Evaluation at a PTCOE is important for patients with Cushing's syndrome
- The framework for PTCOE is still to be established
- The voice of patient support and advocacy groups must be heard by legislators and insurance companies

*Thank you!*