UCSF
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AQUA, BAUS, and other registries: a critique

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BAUS Section of Oncology Annual Meeting
Cardiff, UK

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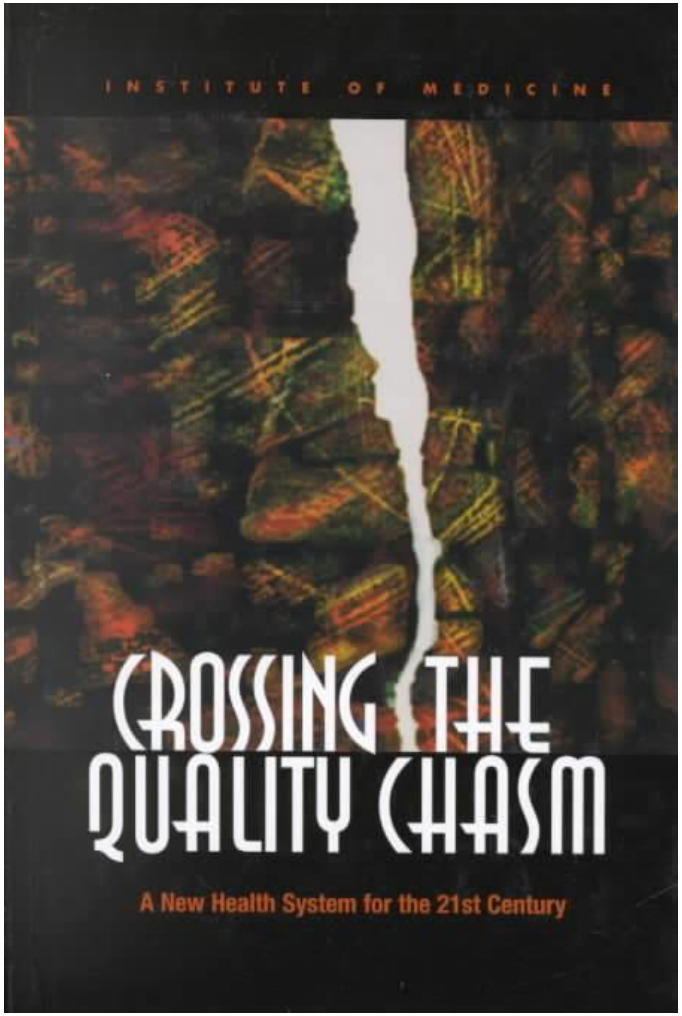
@dr_coops

Disclosures

I am the Senior Physician Advisor for the AUA Quality (AQUA) Registry

We've been talking about quality for years…



…but little consensus on what/how to measure and report

In 2016 quality reporting is here—*for better or worse*

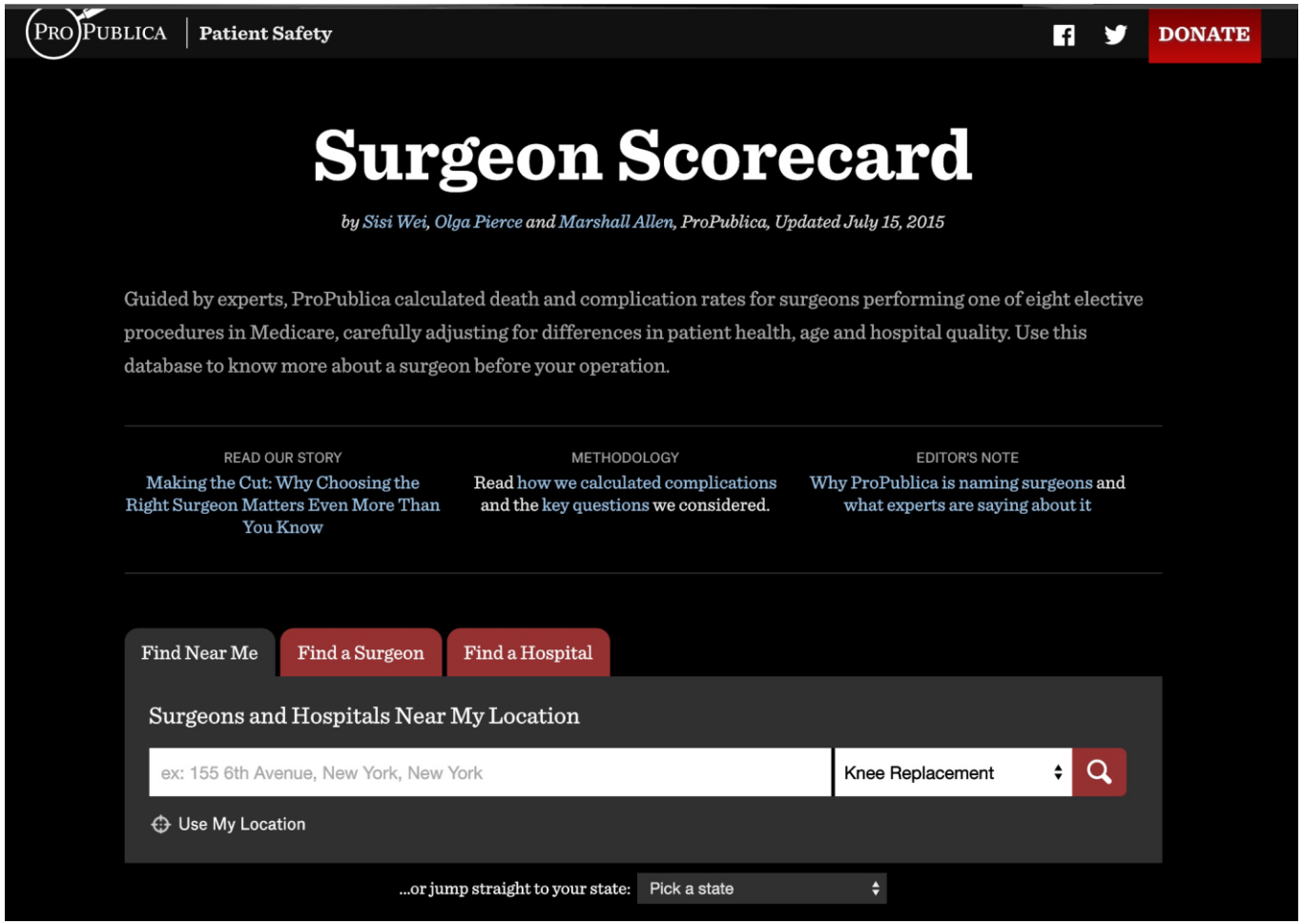
MIPS

1. Quality Reporting (PQRS)
2. Value-Based Payment Modifier
3. EHR "Meaningful Use"
4. Clinical Practice Improvement (New)

The cost of nonparticipation

Payment Year	Performance Year	PQRS Penalty	VBM Penalty	MU Penalty	Total Penalties
2015	2013	1.5%	1%	1-2%	3.5-4.5%
2016	2014	2%	2%	2%	6%
2017	2015	2%	4%	3%	**9%**
2018	2016	2%	TBD	3-4%	TBD
2019	2017	2%	TBD	3-5%	TBD

Quality reporting is “Garbage in, Garbage out”



projects.propublica.org/surgeons/

We need real *data*

EUROPEAN UROLOGY XXX (2015) XXX–XXX

available at www.sciencedirect.com
journal homepage: www.europeanurology.com

European Association of Urology

Platinum Priority – Prostate Cancer

Editorial by XXX on pp. x–y of this issue

Prostate Cancer Registries: Current Status and Future Directions

Giorgio Gandaglia [a,], Freddie Bray [b], Matthew R. Cooperberg [c], R. Jeffrey Karnes [d], Michael J. Leveridge [e], Kim Moretti [f], Declan G. Murphy [g], David F. Penson [h], David C. Miller [i]*

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Research registries

- Scandinavia: PCBaSe, registries in Norway, Denmark
- Emerging pan-Asia: A-CaP
- Australia/NZ: PCOR-ANZ
- UK: National Cancer Registration Service + Biobank
- US: SEER, SEER-Medicare, NCDB, NIS, CaPSURE, CPDR, SEARCH, Canary-PASS

SEER (Surveillance, Epidemiology, and End Results)

- US database maintained by NIH/NCI since 1971
- Comprises 10 states, 2 metropolitan areas, and 3 Native American cancer registries (report by local registrars), ~28% of US cancer patients
- Largely representative of whole population from demographic perspective (weighted toward urban)
- Basic clinical information
  - PSAs since 2004 (under scrutiny for decimal errors)
- Limited treatment data
- Good followup, highly valuable extensions studies (e.g., PCOS, CEASAR)
- Incomplete capture of outpatient diagnoses
- Straightforward access

SEER-Medicare

- Merges SEER with Medicare part A&B files
- Major advantage: much more detail re: workup, treatment, followup, etc., than SEER alone
- Major disadvantages:
  - Only people >65 (and in SEER regions)
  - Only people (continuously) in Medicare fee-for-service
  - Coding data are questionably accurate
  - For e.g., prostate cancer, only ~1% of patients are included
- Relatively long lag times
- Complex access

NCDB (National Cancer Data Base)

- Maintained by American College of Surgeons Commission on Cancer
- Includes ~25% of hospitals / ~75% of patients (similar reporting format as SEER)
- Substantially inpatient-focused
- Similar data as SEER

NIS (Nationwide Inpatient Sample)

- 20% sample of all hospital admissions
- Includes administrative discharge data (largely code-based)
- Includes non-cancer conditions
- Straightforward access

- N=7 in Eur Urol

CaPSURE

- Started at UCSF in 1995 (originally funded by TAP)
- 47 urology practices have ever participated (12 ongoing)
- >15,000 men (~5,000 actively followed), long term followup
- ~1000 variables (clinical reported by sites via web, PROs report by patients mostly on scannable paper)
- >180 papers (3 in Eur Urol)
  - Health services utilization
  - Clinical outcomes
  - Patient-reported outcomes
- Coming soon: genomic analyses

SEARCH

- 4 Veterans Affairs and 1 military hospital
- “Equal access” health system
- High representation of African-American patients
- Historically, RP only
- N=4 in Eur Urol

- Shifting to national data extraction via VINCI
- Expanded focus to CRPC

Quality of care registries

- NSQIP
- MUSIC
- PURC
- AQUA
- BAUS

MUSIC

- Statewide quality collaborative in Michigan established 2011
- 42 practices (90% of urologists statewide)
- Funded by Blue Cross / Blue Shield
- Primary goal is quality improvement, includes face-to-face meetings among urologists to set goals and review data

The AUA Quality (AQUA) Registry

Collect detailed national process and outcomes data for patients with urologic diseases

- Primary goal: quality assessment and improvement through local feedback to practices
- Secondary goals: fuel next-generation HSR and clinical / outcomes research; inform urology policy efforts

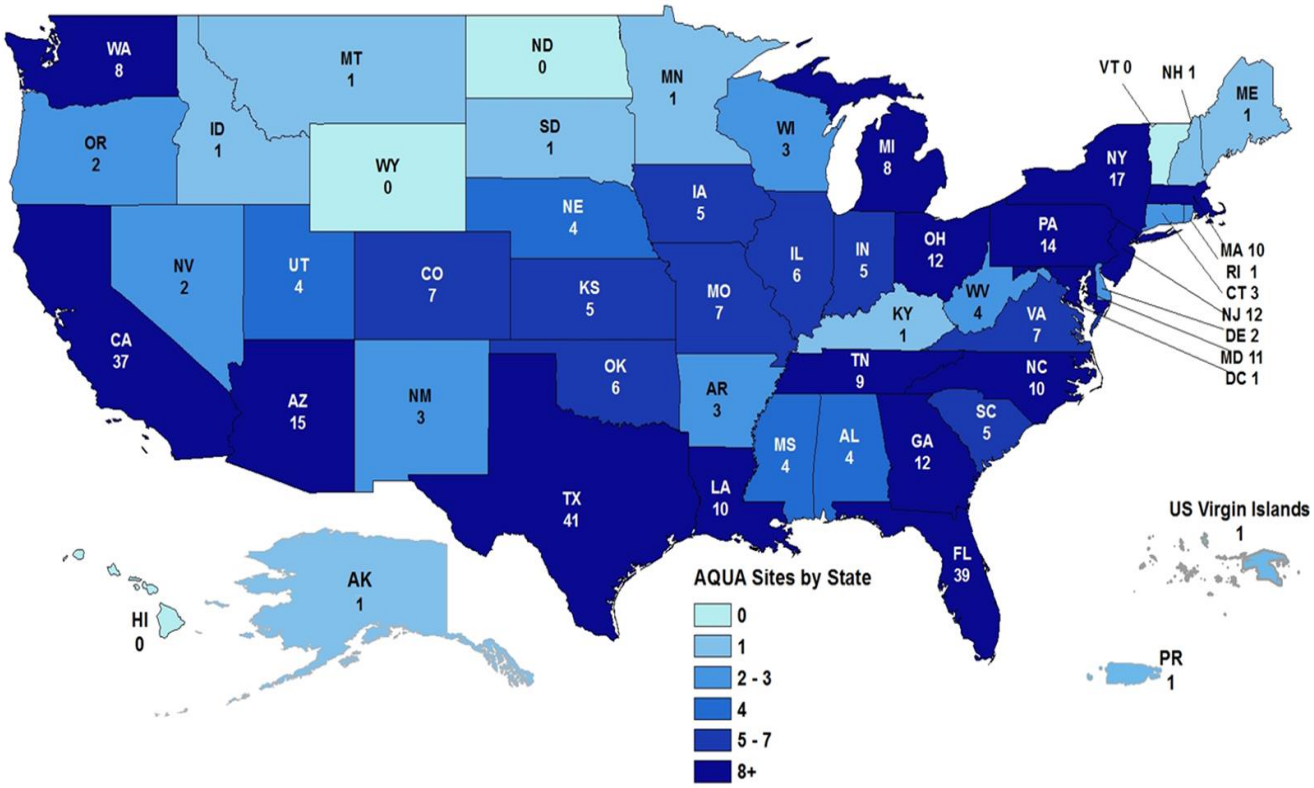
Key principles

- Software (FIGMD) to minimize data entry burden – access to both structured and nonstructured data
- Data ownership by individual practices and the AUA only
- Practice-level data will be shared only with the individual practice, benchmarked against the aggregate data. No practice will see any other individual practice's data.
- Incorporate patient-reported outcomes (PROs)

Benefits and Incentives

- Strong financial incentives to streamline quality reporting (MU / PQRS / MIPS) – AQUA has “QCDR” certification
- Eventually credit toward maintenance of certification (MOC)
- Clinician dashboard for patient-level tracking and practice-level QA/QI initiatives
- Patient dashboard for decision support and survivorship
- Improved care through local/internal data exposure
- “Next-generation” research opportunities for health services, outcomes, and comparative effectiveness research

Recruitment update



N=419 sites, >2500 providers

(Data from ~15% of sites)

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NLP update

The patient is a 62 year old male who presents with prostate cancer. Today's reason for visit is for a routine follow-up. Date of initial diagnosis: 6/10/14. The initial diagnosis reveals a prostate nodule, 8 cores on biopsy, 80 percent of cores with cancer (on left, 70% on right), a Gleason score 3+4 and PSA 54.1 (3/25/14). Initial imaging studies include abdomen and pelvis CT scan (6/18/14 prostate indenting bladder, bladder wall thickening, no metastatic disease, fatty liver, multiple bilateral renal cysts, constipation with diverticulosis) and a bone scan (6/18/14 abnormal with 2 foci in the midshaft of right femur). Past evaluation has included a(n) abdomen and pelvis CT (most recently 9/15/14 3.7cm right iliac fluid) and a bone scan. Past treatment has included robotic radical prostatectomy (8/21/14 bilateral non-nerve sparing, bilateral node dissection, extremely difficult) and radiation therapy (started 6/2015). The Gleason score is (4+5). PSA was last measured on 12/5/14 and PSA value was 1.22. TNM stage is T3b, N0 and M0 (clinical) . ?The symptoms present are dysuria, hematuria (following radiation on Monday), incontinence (he remains incontinent, he has been going through several pads per day and leaks mainly at night, he has started PT and is working with this and has been improving overall, some of the leakage from the standpoint of dripping is better, he is still getting urgency spasms, his control has improved but his urgency, etc. is worse with the radiation), urinary frequency and urinary ur
denies bone pain, reduced urinary stream or weight loss. The following surveys w
24 ?prior to Flomax. Tumor markers include elevated PSA. Pathology shows High ri
8+ T2c), extra capsular extension positive (extensive throughout the entire glar
invasion positive (with invasion of vas deferens bilaterally), positive multi-ma
all margins including apex and bladder neck) and lymph nodes invasion negative.
referred by an urologist (Dr. Donald Duck). Pertinent medical history includes b
hypertrophy, obesity, hypertension, previous abdominal surgery (left inguinal he
other (OSA, but does not use his CPAP regularly), while the patient's history do
diabetes or heart disease. The patient has the following preventative measures c
supplementation. Note for "Prostate cancer": He underwent a NaF PET scan on 7/3(
for metastatic disease. Cystogram on 8/28/14 and 9/11/14 show persistent extrava
sampled Myrbetriq at the 8/28/14 appointment. He underwent another cystogram on
persistent leak but much improved. He ended up undergoing a cystoscopy with Fole
10/20/14 which showed a complete breakdown and a walled off area on the left lat
anastamosis. He has an area that is bothering him in the same location of the pr
his hip that sounds neurologic. He was started on Neurontin.

Element	Value	Date	Date From Note
Total Gleason	7		
Total Gleason	9	6/1/2015 12:00:...	6/2015
Primary Gleason	3		
Primary Gleason	4	6/1/2015 12:00:...	6/2015
Secondary Gleas...	4		
Secondary Gleas...	5	6/1/2015 12:00:...	6/2015
Total Biopsy Cores	8		
PSA	54.1	3/25/2014 12:00...	3/25/14
PSA	1.22	12/5/2014 12:00...	12/5/14
cT	3b		
cT	2c		
cN	0		
cM	0		
Diagnosis Date	06-10-2014	6/10/2014 12:00...	6/10/14

Order from chaos (slowly)

2016 AQUA QCDR Measures

PQRS measures

1. VTE prophylaxis
2. Medication reconciliation
3. Advance care plan
4. Assessment of urinary incontinence (women)
5. Plan of care for women with incontinence
6. Avoiding bone scan for low-risk prostate cancer
7. Use of ADT with radiation for high-risk prostate cancer
8. Influenza screening

2016 AQUA QCDR Measures

9. Colorectal cancer screening
10. Nephropathy screening for diabetics
11. BMI screening and followup
12. Documentation of medication list
13. Pain assessment and followup
14. Tobacco screening and cessation counseling
15. Controlling high blood pressure
16. Biopsy followup communication
17. HTN screening and followup
18. Alcohol screening and followup

2016 AQUA QCDR Measures

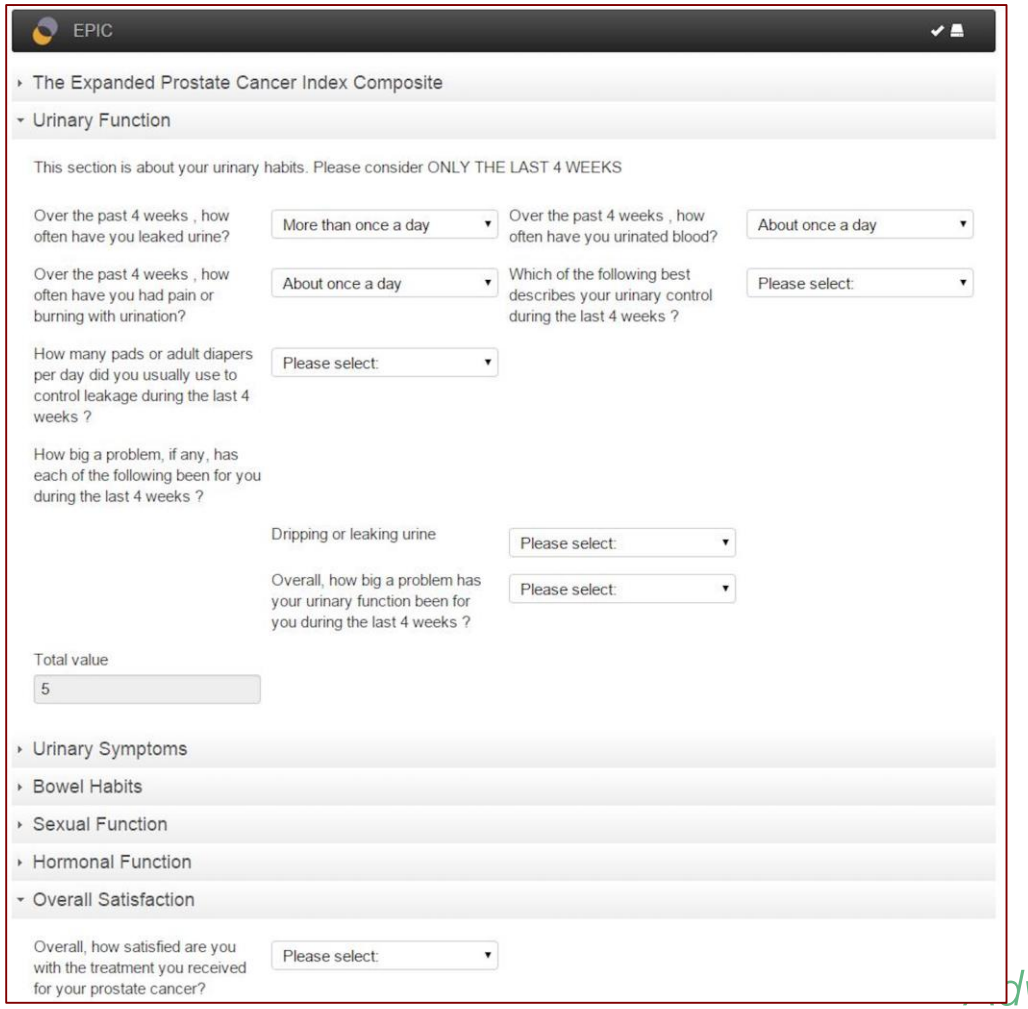
Non-PQRS measures (Derived from AUA guidelines)

1. Prostate cancer: documentation of stage, 1° /2° Gleason grade, and clinical stage in the provider notes
2. Prostate cancer: Documentation of number of biopsy cores taken / positive in provider notes
3. Cryptorchidism: Non-use of ultrasound
4. Hypogonadism: Testosterone level ordered within 6 months of starting testosterone treatment
5. BPH: Do not order creatinine
6. BPH: Do not order upper tract imaging

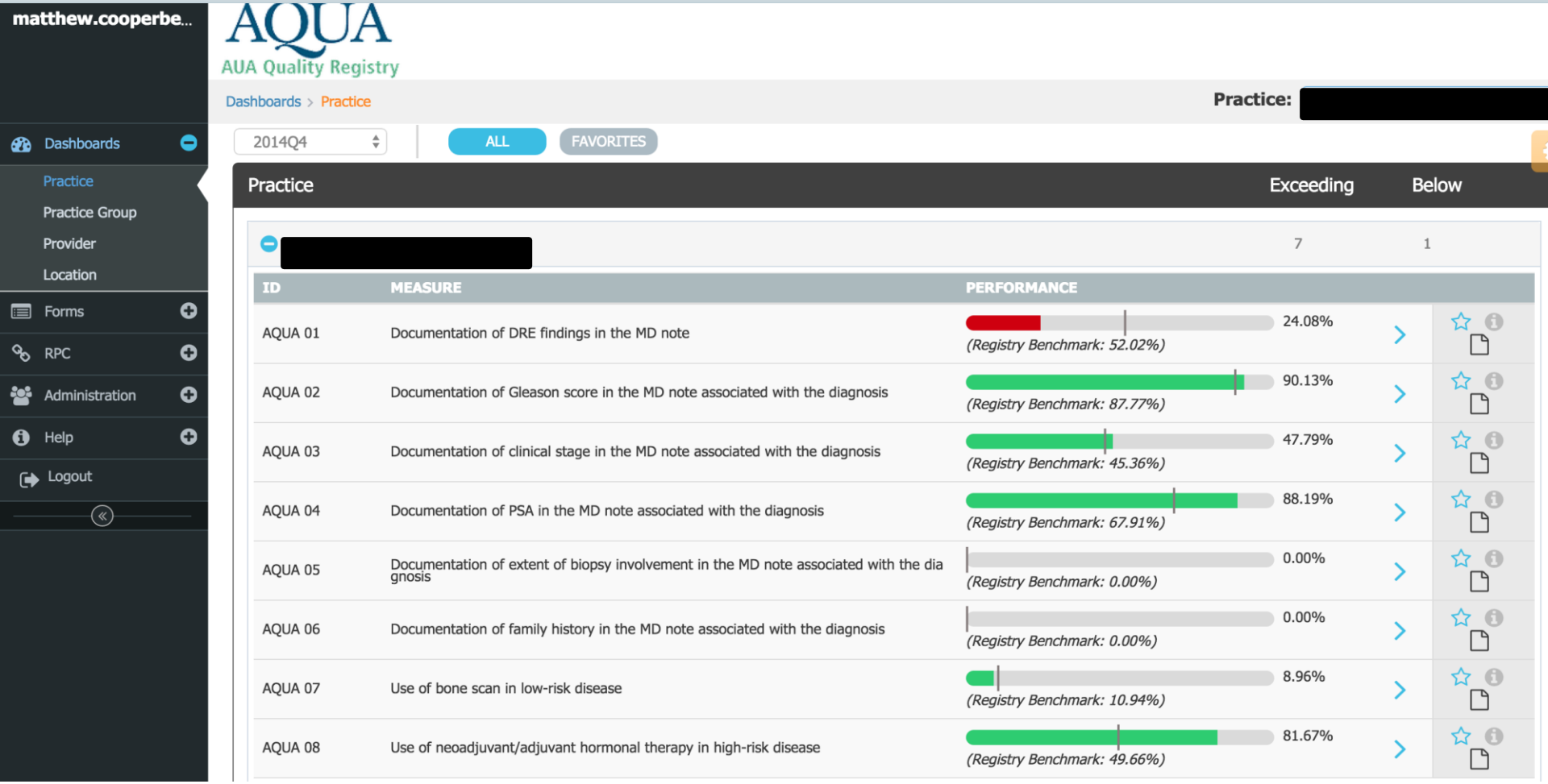
2016 AQUA QCDR Measures

7. BPH: IPSS change from baseline to 6 months after diagnosis (outcome)
8. Prostate biopsy: re-admission / complication within 30 days (outcome)
9. Prostate cancer: use of active surveillance / watchful waiting for men with low-risk disease (outcome)
10. Prostate cancer: urinary function 12 months after primary treatment (outcome – PRO)
11. Prostate cancer: sexual function 24 months after primary treatment (outcome – PRO)

Collecting PROs *nationally*



Dashboard preview



Dashboard preview

[redacted]

AQUA 02 : Documentation of Gleason score in the MD note associated with the diagnosis

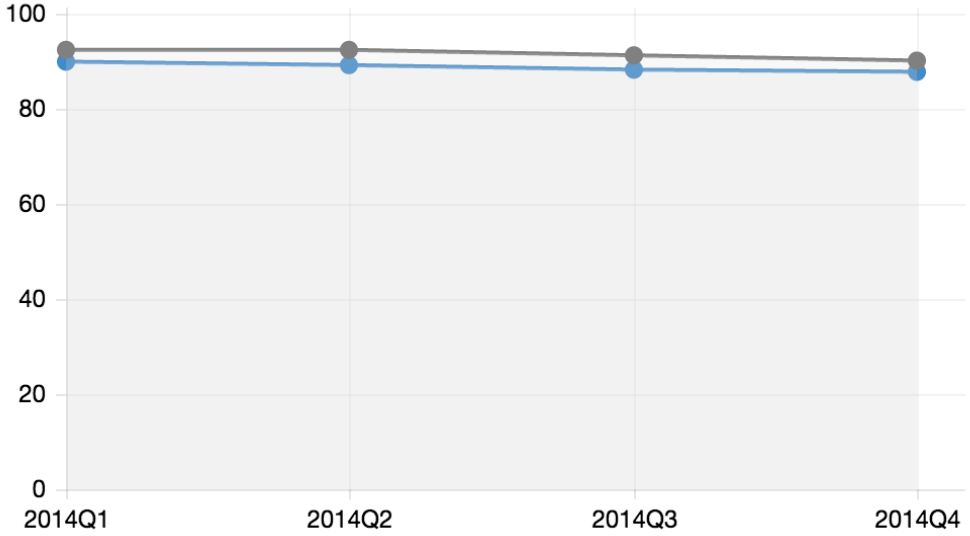
90.13 %

Registry Benchmark 87.77 %

PERFORMANCE TREND | LOCATIONS | PROVIDERS | ALL

PERFORMANCE TREND

PERFORMANCE REGISTRY BENCHMARK



QUARTER	ALL	(+)	(-)	%
2014Q4	1084	977	107	90.13 %
2014Q3	1004	916	88	91.24 %
2014Q2	920	850	70	92.39 %
2014Q1	907	838	69	92.39 %

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Dashboard preview

[redacted]

AQUA 02 : Documentation of Gleason score in the MD note associated with the diagnosis

90.13 %

Registry Benchmark 87.77 %

PERFORMANCE TREND | LOCATIONS | PROVIDERS | ALL

PROVIDER NAME	QUALIFIED (ALL)	MET (+)	NOT MET (-)	PERFORMANCE
[redacted]	12	11	1	91.67% (Registry Benchmark: 87.77%)
	16	13	3	81.25% (Registry Benchmark: 87.77%)
	28	25	3	89.29% (Registry Benchmark: 87.77%)
	20	20	0	100.00% (Registry Benchmark: 87.77%)
	20	19	1	95.00% (Registry Benchmark: 87.77%)

Template update

- Set of prostate cancer templates built in Epic and moving to Foundation repository.
- These can be adapted for other EMRs
- Active work ongoing for Allscripts and NextGen
- In some EMRs, structured data may be captured via templates or forms, else templates facilitate NLP
- Templates speed clinical workflows as well

BAUS prostatectomy data 2014-15

- 13,949 cases (95% in England): 164 surgeons at 74 practices. 95% capture of cases in England
- Median per center 151 (75 / year), range 1-595
- Median per surgeon 66 (33/year), range 1-315

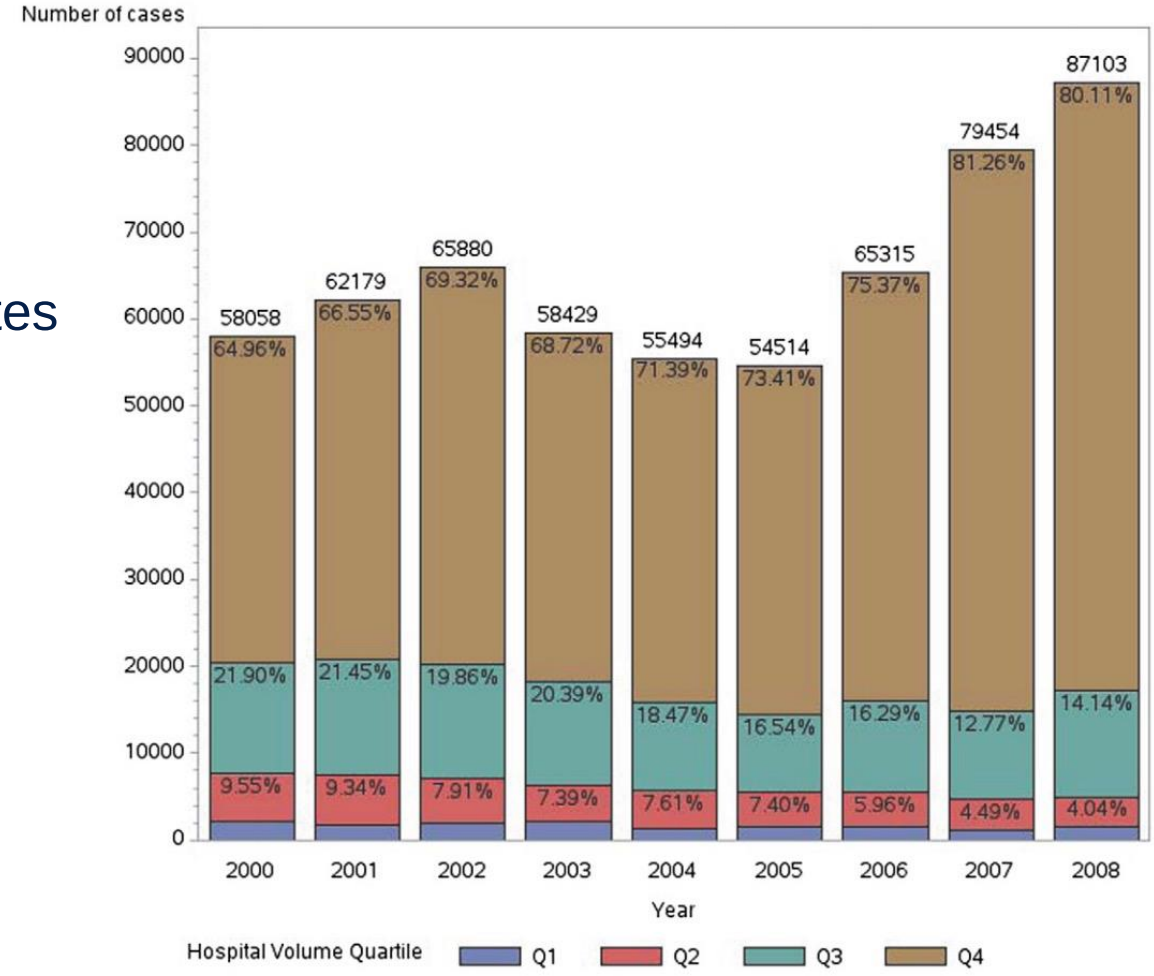
	NIS		SPARCS	
Annual Caseload	% Surgeons (933)	% Pts Seen	% Surgeons (393)	% Pts Seen
1	26.9	3.8	27.0	2.6
2	16.2	4.6	16.5	3.2
3	9.4	4.0	8.4	2.4
4	6.3	3.6	6.6	2.5
5	7.1	5.0	4.8	2.3
6–10	16.9	18.4	15.3	11.3
10 or Fewer	82.9	39.3	78.6	24.4
11–24	13.3	28.2	13.0	18.7
25 or More	3.9	32.4	8.4	56.9
50 or More	1.8	22.8	4.1	42.9

Begg et al. NEJM 2003;348:2177

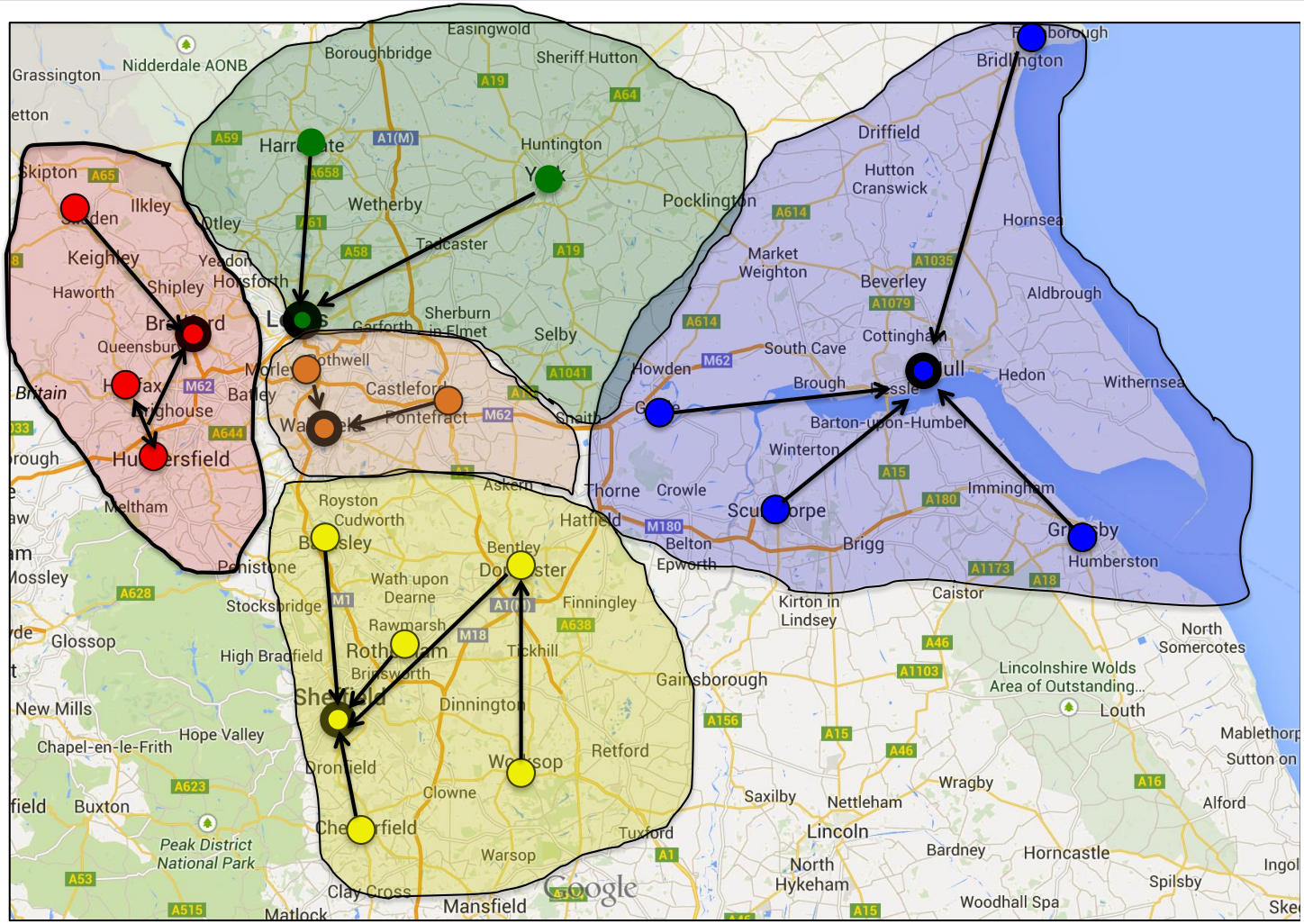
RARP in UK is more far regionalized than in the US

Hospital threshold estimates

Q1 <20
Q2: 20-55
Q3: 55-170
Q4: >170



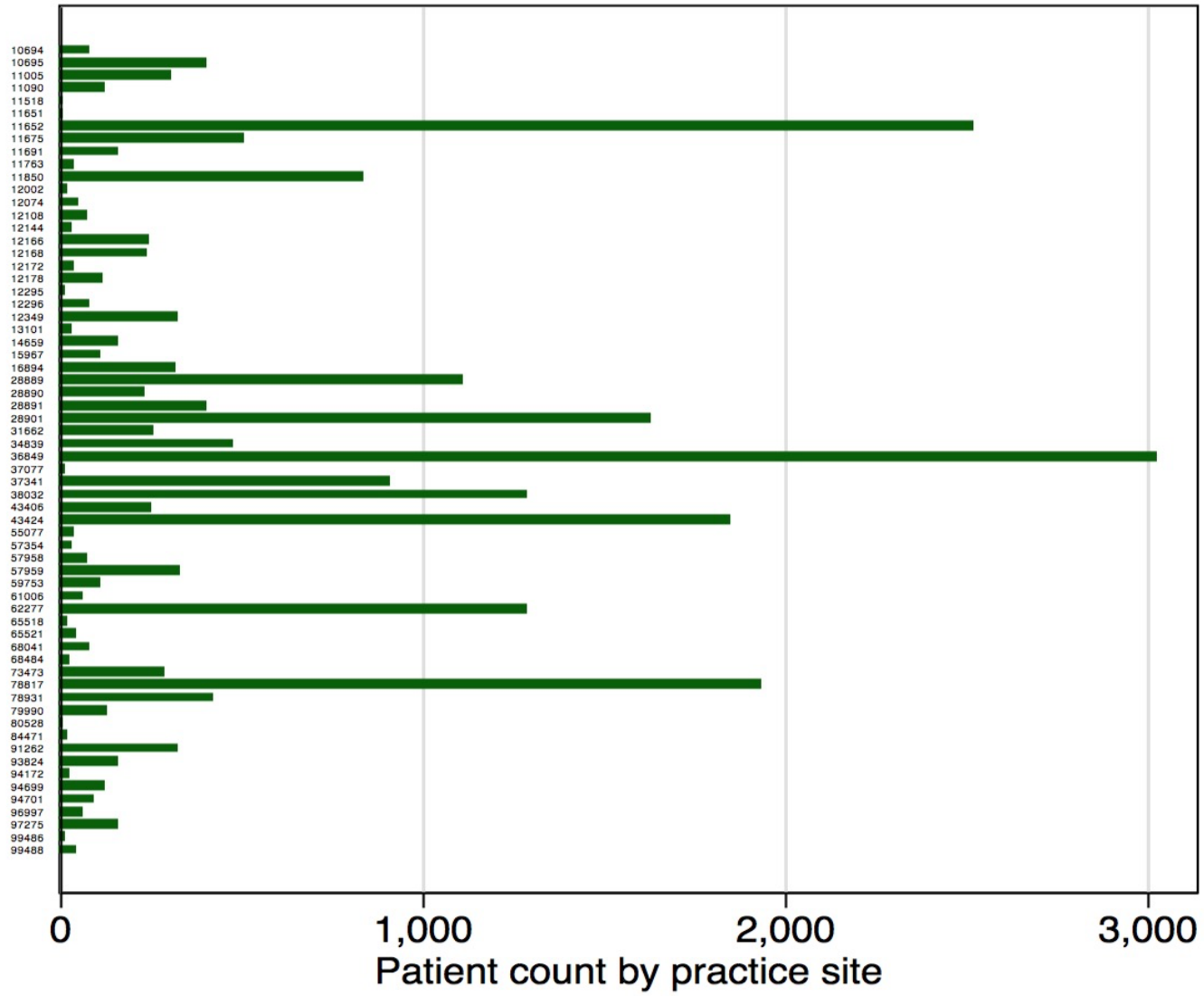
Explicit regionalization



Courtesy of Jim Catto

Prostate cancer diagnoses in AQUA

N=24,007 newly dx'ed prostate cancer



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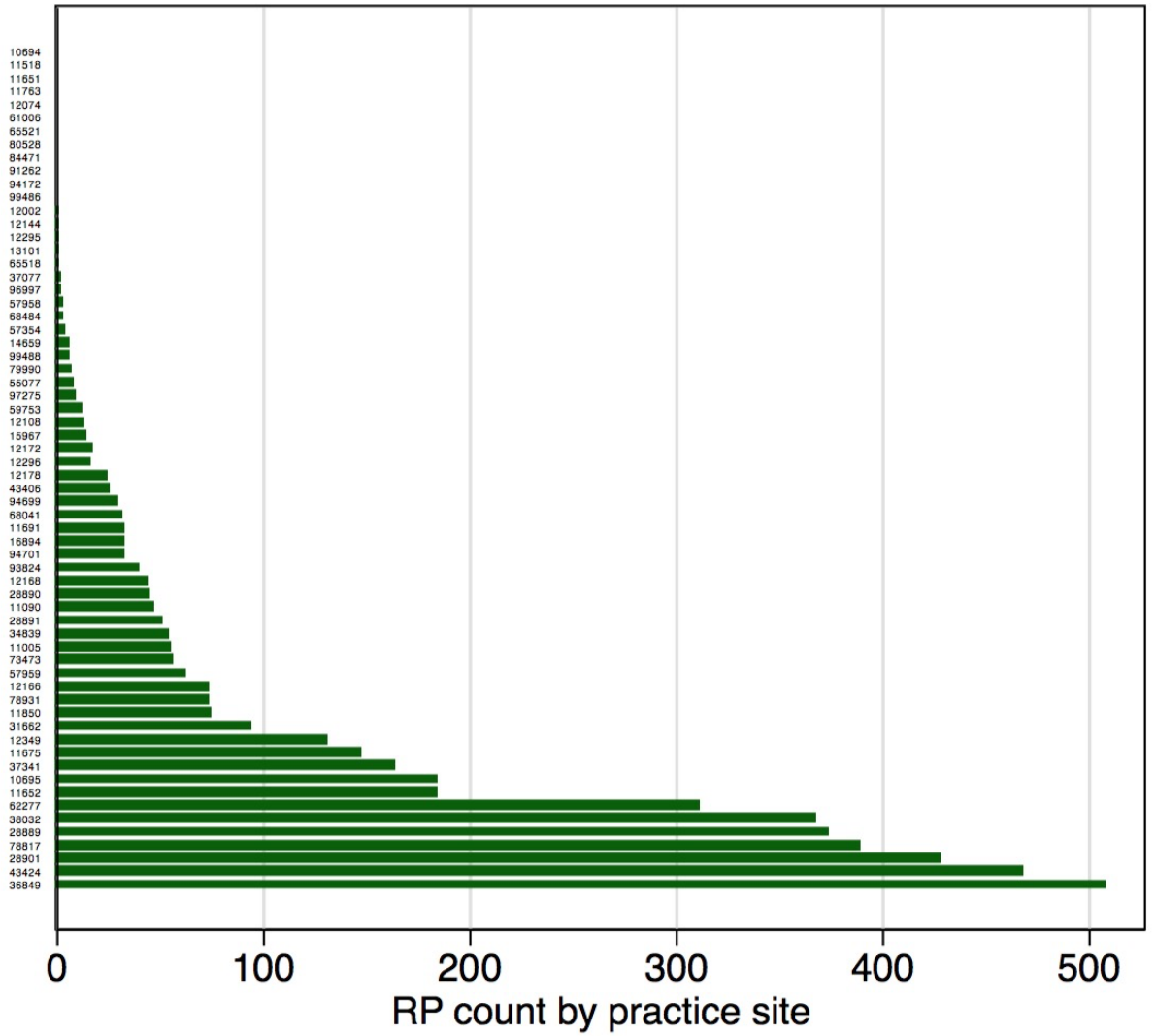
RPs in AQUA

N=4213
RPs 2014-15

Range 1-512



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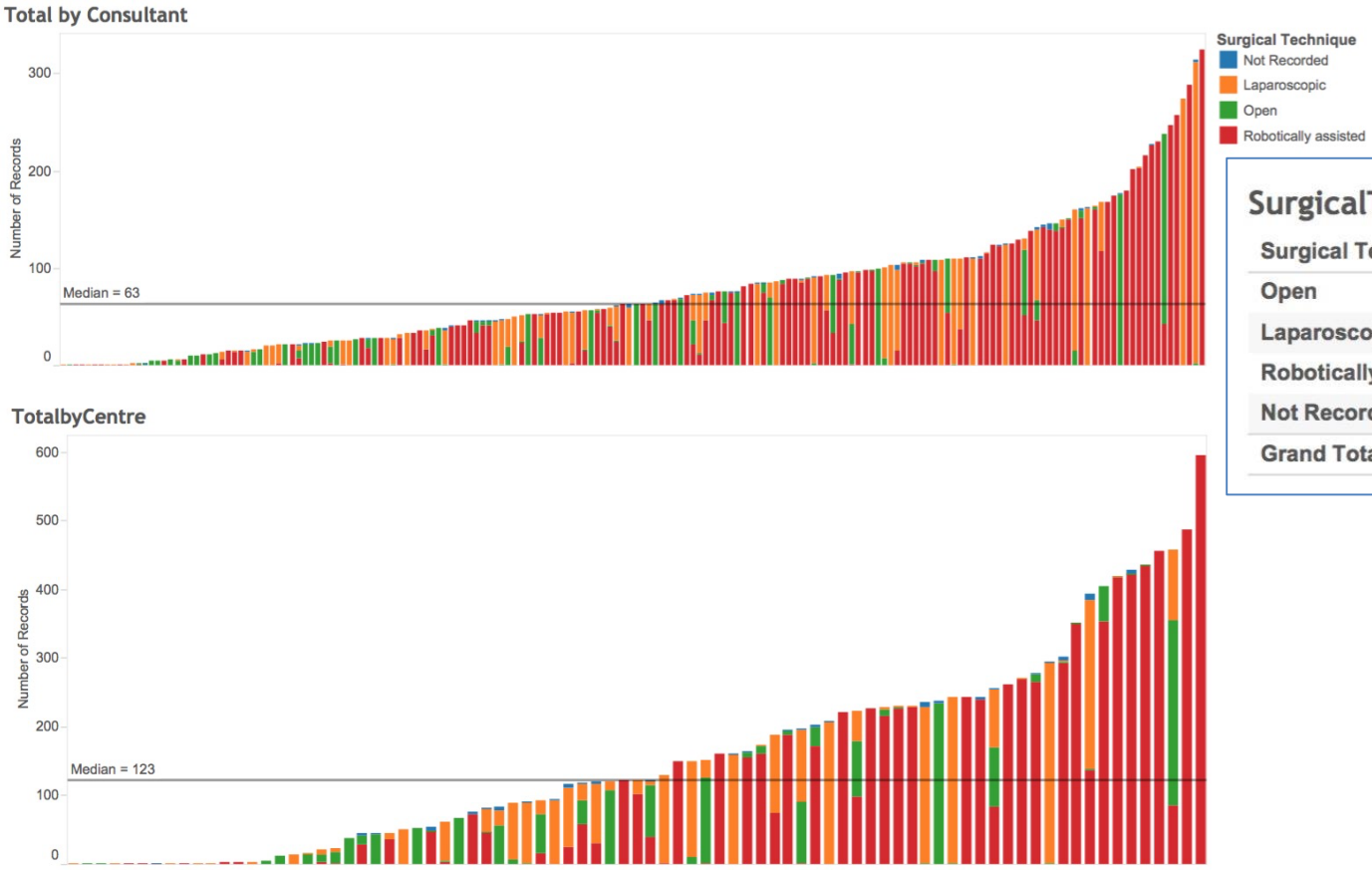
RPs in BAUS

Radical Prostatectomies performed between 01/01/2014 and 31/12/2015 -13,949 cases reported by 180 consultants from 87 sites
(including 987 private cases from 75 consultants)



SurgicalTechnique

Surgical Technique	N	% Total
Open	1,738	12.46%
Laparoscopic	3,139	22.50%
Robotically assisted	8,984	64.41%
Not Recorded	88	0.63%
Grand Total	13,949	100.00%

Transfusion rates

BAUS: 3.7% open, 0.8% lap, 0.5% robotic

- SEER-Medicare 2003-07: 20% open, 2.5% robotic (Hu et al. JAMA 2009)
- NIS 2009: 8.2% open, 2.0% robotic (Sammon et al, J Urol 2013)
- Meta-analysis 2012: 16.5% open, 4.7% lap, 1.8% robotic (Tewari, Eur Urol 2012)

Complication rates

BAUS: 8.1% overall (1.6% Clavien-Dindo ≥3)

Clavien Dindo Grade of Post-Operative Complications by Technique

		Surgical Technique									
		Laparoscopic		Open		Robotically assisted		Not Recorded		Grand Total	
Postop Com..	Clavien Dind..	N	% Total	N	% Total	N	% Total	N	% Total	N	% Total
Post op Complication	Grade I	86	3.19%	38	2.43%	198	2.57%	2	2.86%	324	2.69%
	Grade II	77	2.85%	55	3.52%	132	1.72%	2	2.86%	266	2.21%
	Grade III plus	42	1.56%	32	2.05%	114	1.48%	3	4.29%	191	1.59%
	Not recorded	56	2.07%	70	4.48%	69	0.90%	2	2.86%	197	1.64%
	Total	261	9.67%	195	12.47%	513	6.67%	9	12.86%	978	8.13%
Grand Total		2,699	100.00%	1,564	100.00%	7,691	100.00%	70	100.00%	12,024	100.00%

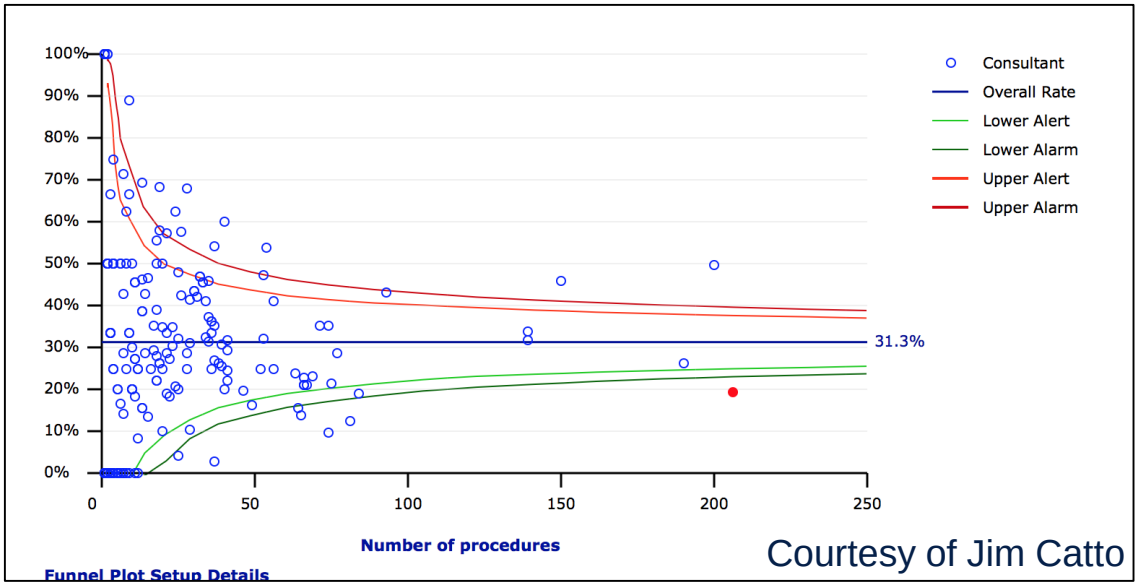
- SEER-Medicare 2003-07: 23.4% open, 21.9% robotic (Hu et al. JAMA 2009)
- NIS 2009: 12.7% open, 8.7% robotic (Sammon et al, J Urol 2013)
- Meta-analysis 2012: no summary

Complication rates

	BAUS	NIS	SEER-Medicare (open/lap-robo	Meta-analysis (open/lap/robo)
Rectal injury	4.3%			0.5/1.0/0.3%
Ureter injury	1.2%			1.5/0.2/0.1%
Anastomotic leak	9.6%			10.0/3.7/3.5%
Lymphocele	4.6%			3.2/1.7/0.8%
DVT/PE	1.6%			1.0/0.5/0.3%
Wound infection	8.4%	0.7/0.5%	1.9/1.6%	2.8/0.7/0.7%
Reoperation	2.1%			2.3/1.9/0.9%

pT2 positive margin rates

	BAUS	Meta-analysis
Open	19.3%	16.6%
Lap	17.5%	13.0%
Robotic	13.8%	10.7%



Courtesy of Jim Catto

Tewari et al. Eur Urol 2012; 62:1-15

Technique reporting

Nerve Sparing

Nerve Sparing	N	% Total
None	5,538	39.70%
Bilateral	4,230	30.32%
Unilateral	3,244	23.26%
Not recorded	937	6.72%
Grand Total	13,949	100.00%

Lymph Node Dissection

Lymph Node Dissection	N	% Total
None	7,802	55.93%
Extended	2,537	18.19%
Obturator fossae	2,521	18.07%
Not recorded	1,089	7.81%
Grand Total	13,949	100.00%

Previous Management

Previous Management	N	% Total
None	11,021	79.01%
Brachytherapy	26	0.19%
HIFU	26	0.19%
Radiotherapy	174	1.25%
TURP	179	1.28%
Null	2,473	17.73%
Cryotherapy	4	0.03%
Hormonal suppression ther..	46	0.33%
Grand Total	13,949	100.00%

A few comments:

- Non-nerve sparing rate higher than expected
- Reporting nodal yield rather than just positive counts may be informative
- Salvage cases should perhaps be excluded from denominator for certain outcomes

Data that perhaps should be added

- Multivariable risk stratification (at least NCCN risk groups, preferably nomogram score / CAPRA / etc)
- Lymph node yield
- Readmission rates
- Surgeon / center should be able to follow trends over time

- Non-surgical management (e.g., overall practice patterns)
- Patient reported outcomes

What should be reported *publicly*?

In the US, PQRS reporting is theoretically public

Going forward, urologists will report on their choice of measures via AQUA to CMS, who may choose to publicize results.

Neither MUSIC nor AQUA includes any public reporting (yet).

Propublica “surgeon scorecard”

MATTHEW COOPERBERG

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(address information updated June 8, 2010)

Related Hospitals:
UCSF MEDICAL CENTER

How we calculated these rates: Guided by top researchers and doctors, ProPublica use… …e a patient died in the hospital or had to be readmitted within 30 days for a problem related … …complication rates for surgeons, carefully accounting for differences in patient health, age a… …from Medicare records, which do not include patients with private insurance or in another… …pitals at which he or she operates and is not unique to a given hospital. Read our methodology…

…items to see details.

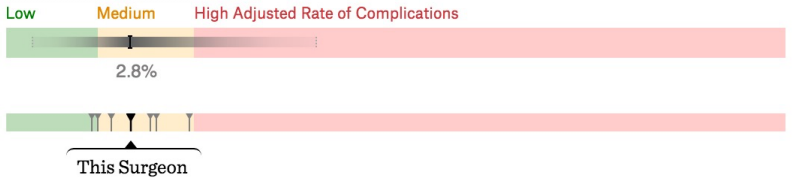
Pr…
Radic… …D-9-CM code 60.5)

The re…oval of the entire prostate gland via the open or laparoscopic or robotic method. Usually performed to treat prostate cancer. More information

This Surgeon

PERFORMED PROCEDURE	COMPLICATIONS	RAW COMPLICATION RATE
39 times	1-10	Redacted

ADJUSTED COMPLICATION RATE



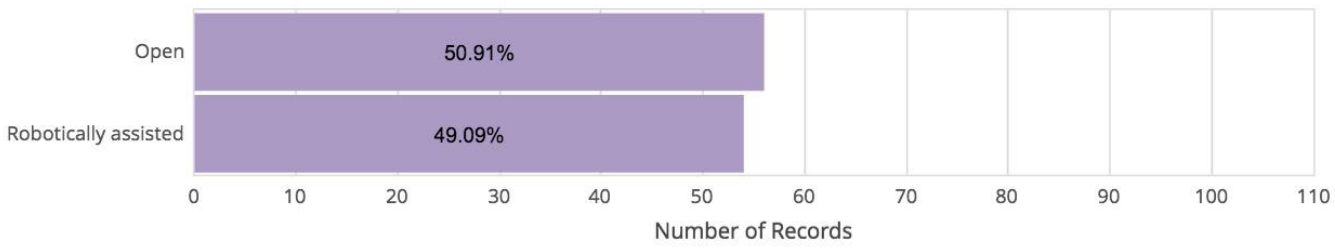
SURGEONS PERFORMING THIS PROCEDURE WITHIN 25 MILES →
SEE AREA HOSPITALS »

This is not better than nothing!

What *should* be reported publicly?

Type and volume of surgery

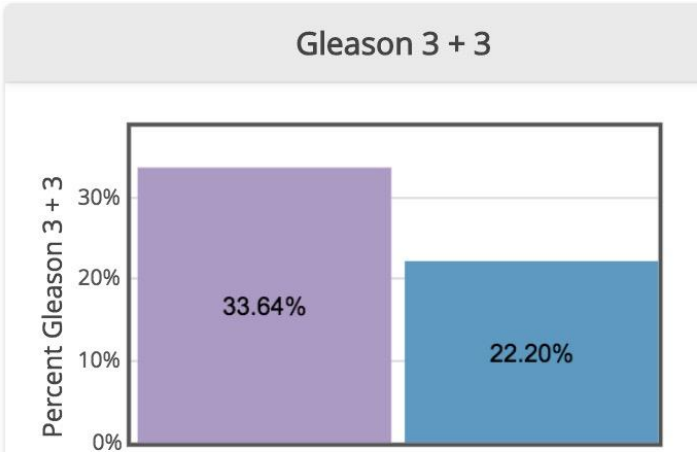
Total by Type

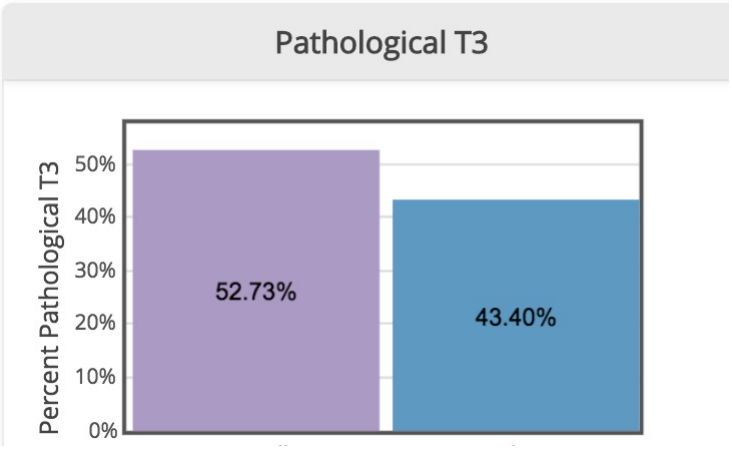


National Figures

	Number	Median	Minimum	Maximum
Open	1737	10	1	196
Laparoscopic	3132	26	1	310
Robotic	8990	57	1	325
Total	**13947**	**63**	**1**	**325**

What *should* be reported publicly?





What *should* be reported publicly?

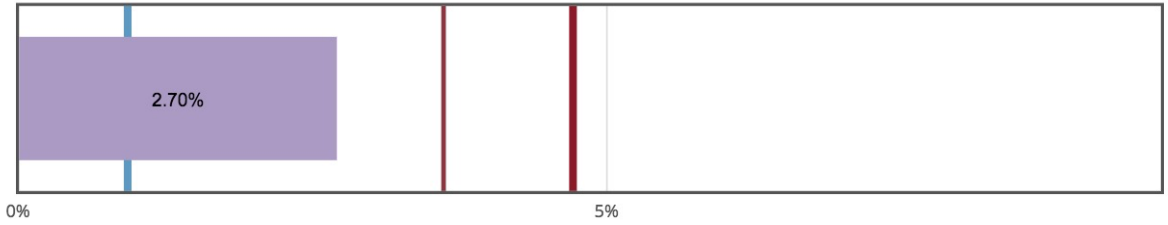
Complications

The light blue line in these graphs indicates national average. The red lines indicate 99% & 99.9% upper alarms.

An empty bar indicates that there were no reported events for that particular outcome. If there is not a chart for either transfusion or complications that indicates that the surgeon did not return any data for this outcome.

Transfusion Rate

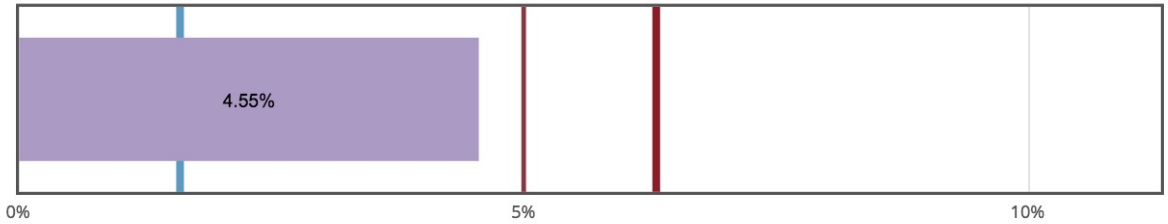
Number of procedures included in transfusion analysis: 110



Complication Rate

The complication rate is for complications graded Clavien Dindo III and above.

Number of procedures included in complication analysis: 110



Concluding thoughts: BAUS

- UK regionalization program is excellent
- BAUS registry has impressive representation of surgical experience nationwide
- You should consider a plan to collect patient-reported outcomes (see ICHOM guidelines)
- Public reporting is doubtless the future—but choose measures wisely, extremely careful risk adjustment is essential, and beware laws of unintended consequences
- Data collection / reporting is burdensome—work toward automation

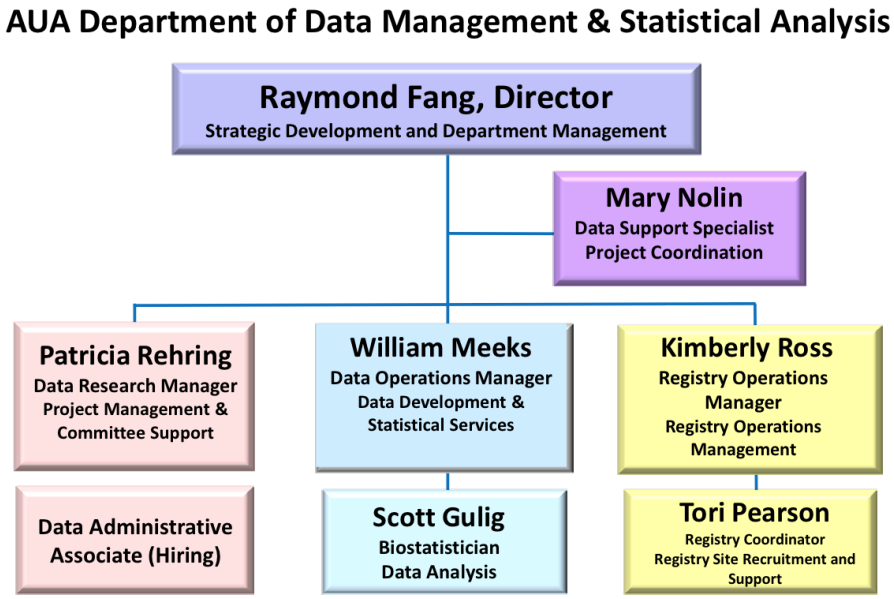
Concluding thoughts: registries

- Databases based on coding/billing data are *the past*
- Prospective registries working from the point of care *and integrating PROs* are *the future* (and the future is now)
- Benign disease catching up (e.g., urethroplasty, stones)
- AQUA scope and size will expand rapidly
- When we can routinely integrate genomics with registries, things will get *really* excited

Thank you: AQUA

The AUA Board of Directors and senior leadership

The AUA Data Committee



All of the early adopter urology practices!

University of California
San Francisco

Thank you!