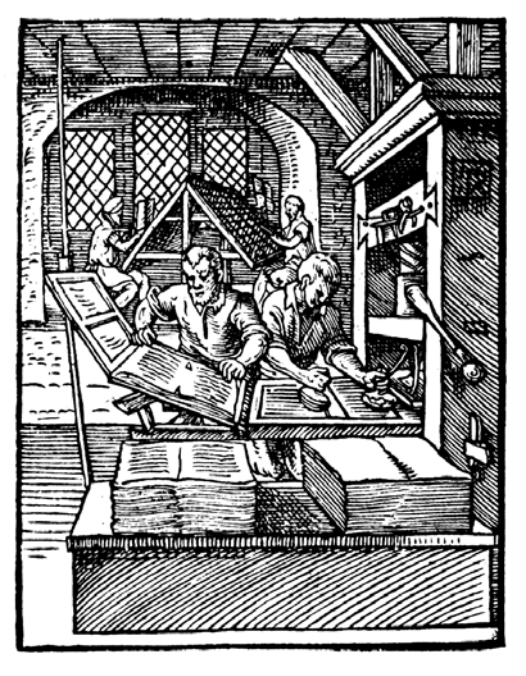
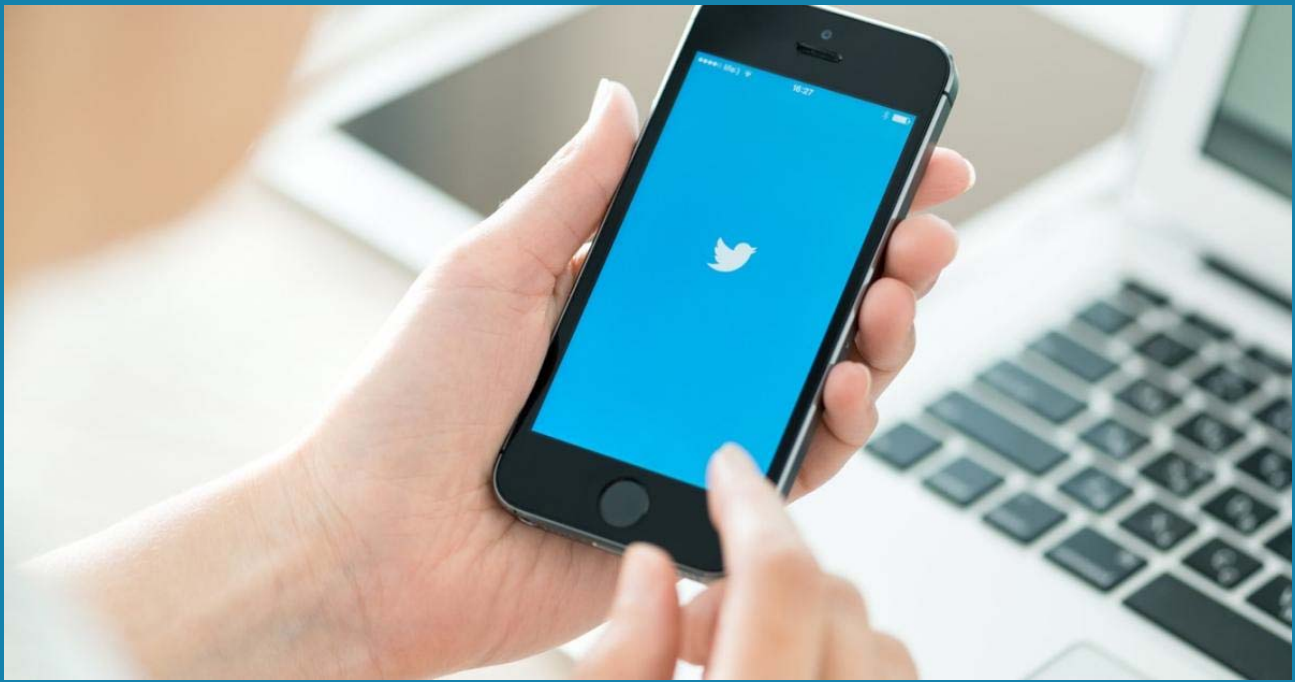
Plenary Speaker

Mark Lewis, MD





THE SECOND COMING OF THE GUTENBERG PRESS: DIGITAL DISSEMINATION OF INFORMATION TO PATIENTS AND PHYSICIANS

Mark A. Lewis, M.D.

SWOG Fall Meeting

Plenary II

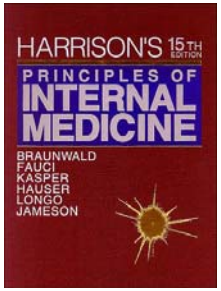
October 4th, 2019

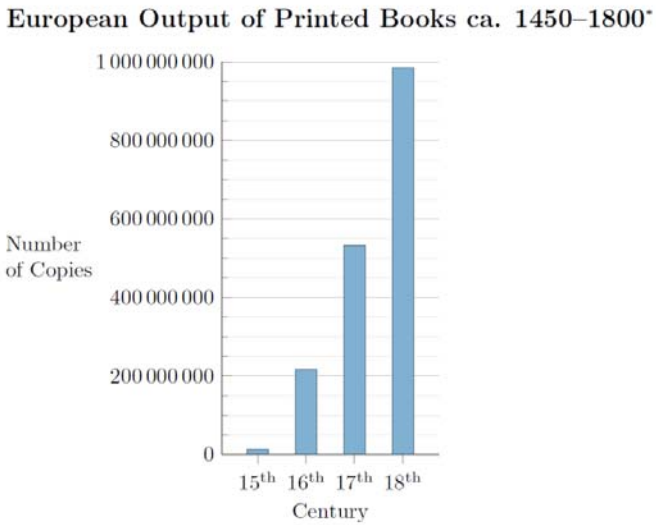
THE PAST AS PROLOGUE

- From the fifteenth century onward, the printed word became the primary vehicle for high-integrity transmission of information

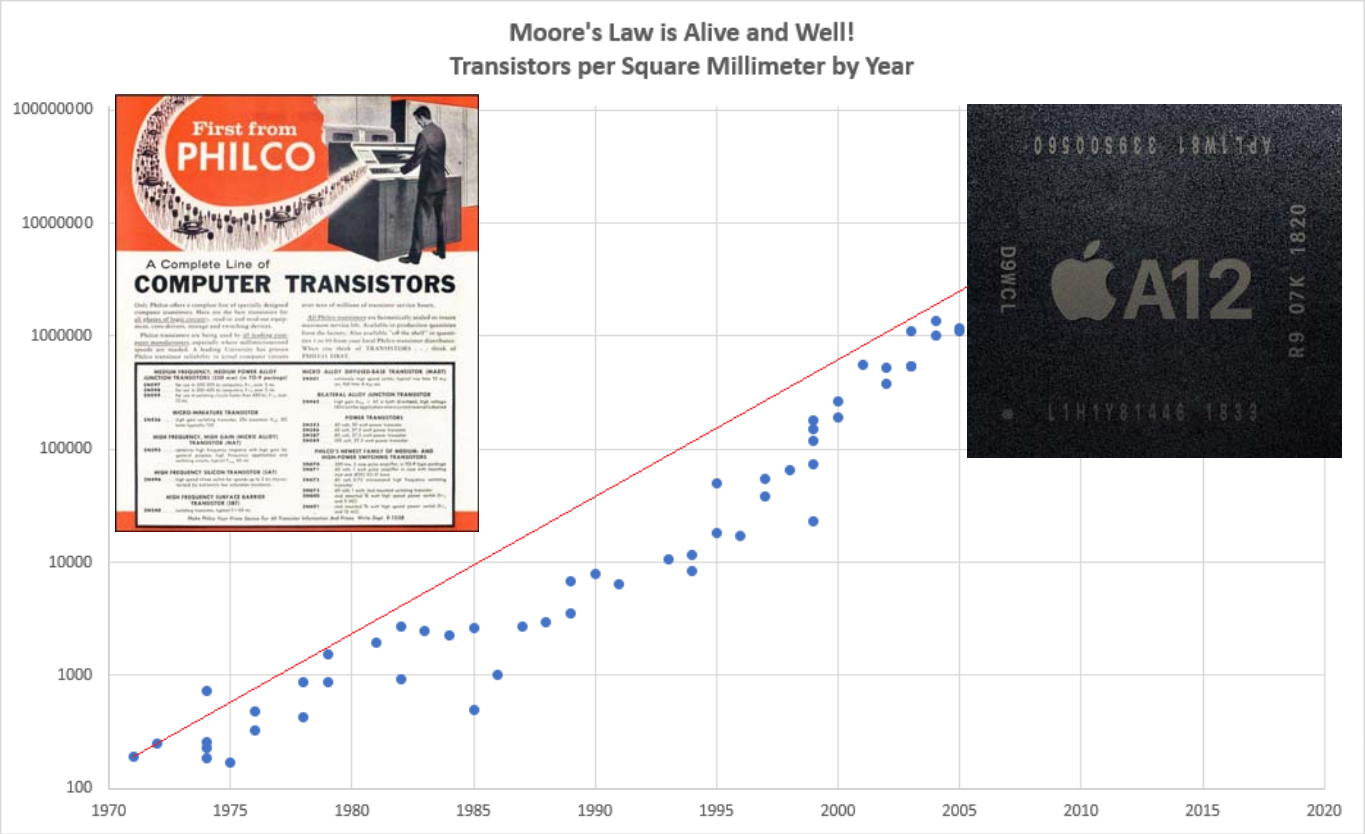
But …

- Means of production were controlled by a select few
- Acquisition of knowledge required substantial resources
- Ink as a medium of programmed obsolescence



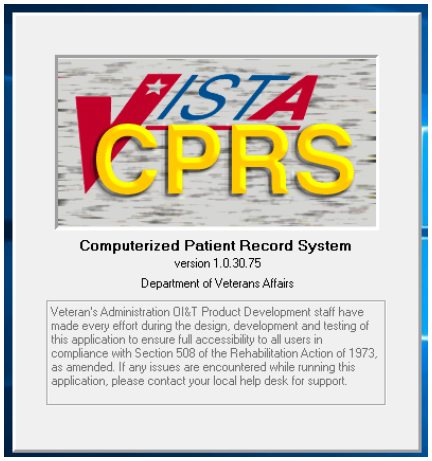


THE PACE OF PROGRESS



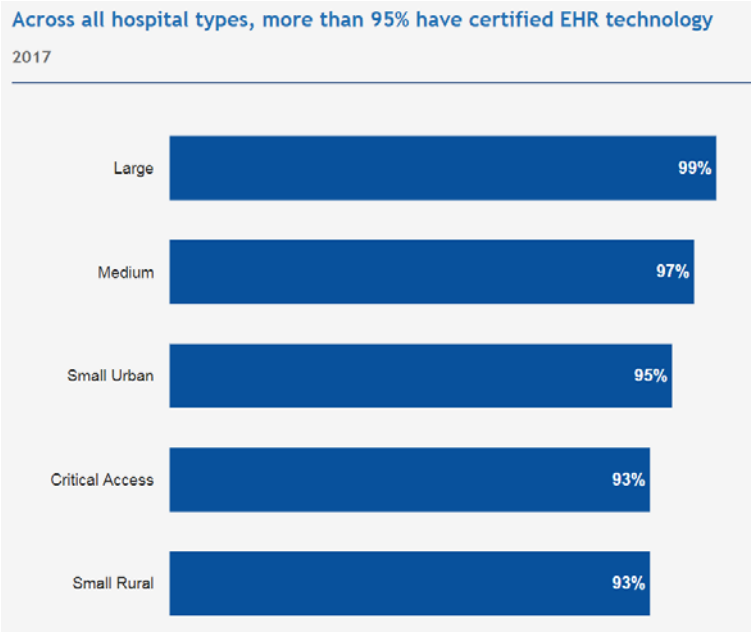
THE PLUMMETING COST OF MEMORY

- 1957: storage cost of one megabyte = $411,041,792 (transistor flip-flop)
- 2019: storage cost of one megabyte = $.0027 ($1/6.56^{12}$ of 1957 prices)
- 2023: projected storage cost of one <u>tera</u>byte = < $10

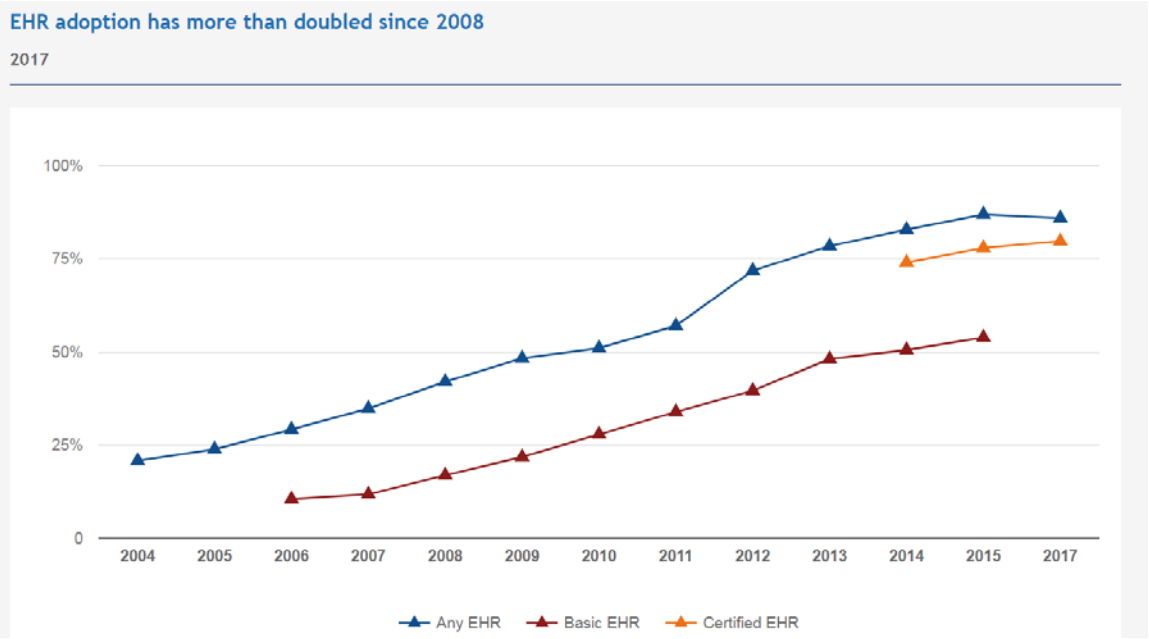


THE ELECTRONIC MEDICAL RECORD

INPATIENT

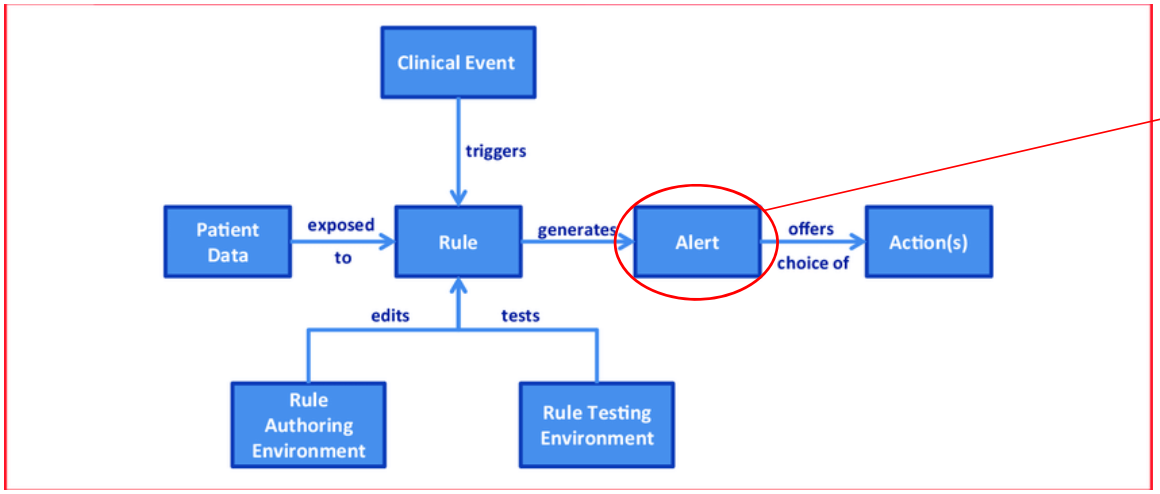


OUTPATIENT



CLINICAL DECISION SUPPORT

Computable biomedical information + patient-specific data + reasoning mechanism = CDS



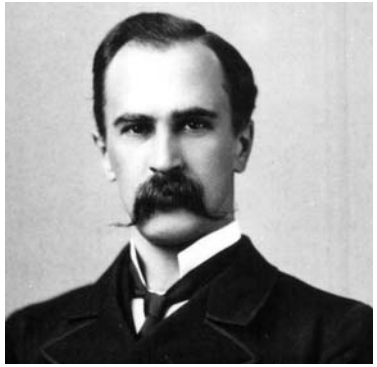
~7% of electronic prescriptions generate alerts, with a 76% override of allergies and a 91% override of drug-drug interactions

Isaac T, Weissman JS, Davis RB, Massagli M, Cyrulik A, Sands DZ, Weingart SN. Overrides of medication alerts in ambulatory care. *Arch Intern Med.* 2009 Feb 9;169(3):305-11.

THE PHYSICIAN AS HUNTER-GATHERER OF DATA

- Physical print quickly becomes outdated & occupies space
- Number of books that can be held on a 256GB iPhone: 192,000 (1 day for ~500 years)
- 'Information paradox': the volume of sources available has made it increasingly difficult to find relevant facts when needed
- Search engines have become vital to the sorting process

GOOGLE AS ANATHEMA TO OUR ARCHETYPE



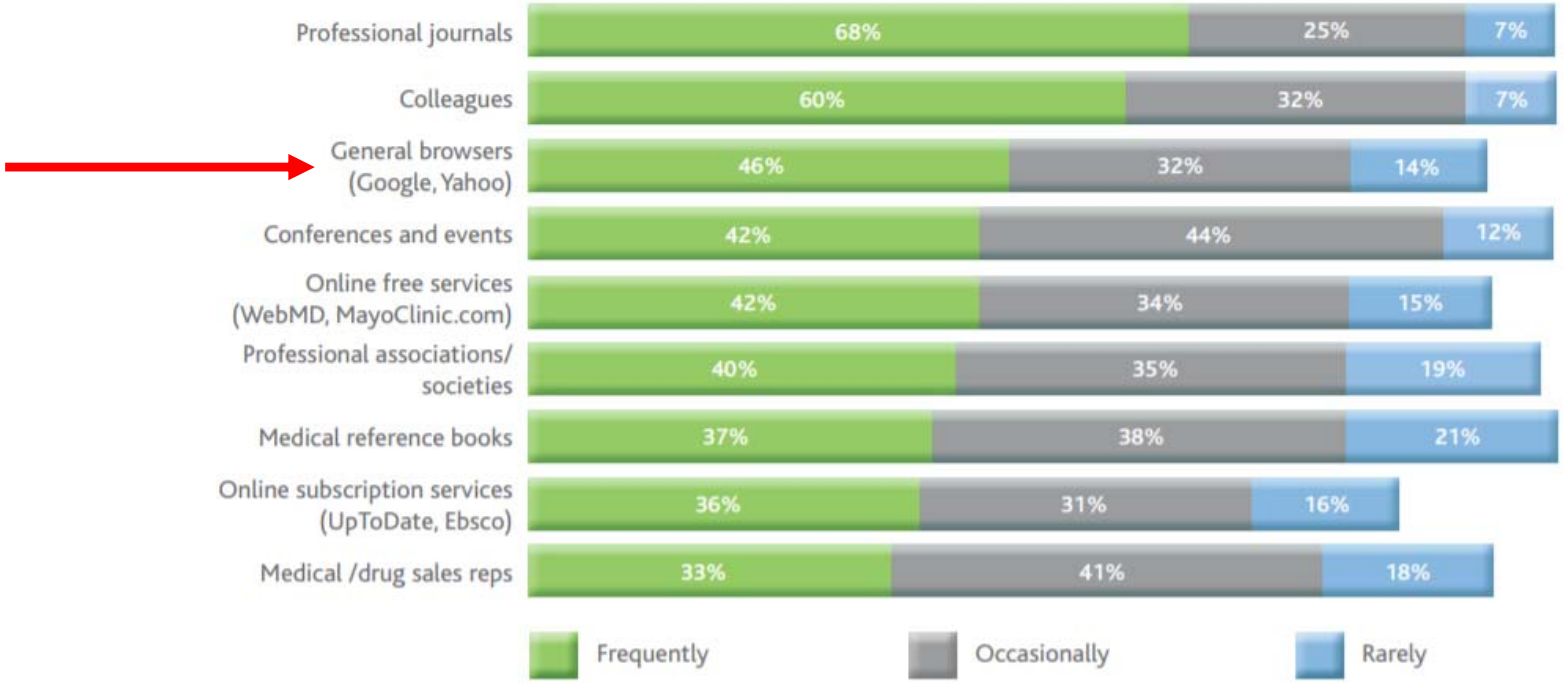
"William Osler," I offered, "must be turning over in his grave. You googled the diagnosis?"

Where does this lead us? Are we physicians no longer needed? Is an observer who can accurately select the findings to be entered in a Google search all we need for a diagnosis to appear, as if by magic? The cases presented at clinicopathological conferences can be solved easily; no longer must the discussant talk at length about the differential diagnosis of fever with bradycardia. Even worse, the Google diagnostician might be linked to an evidence-based medicine database, so a computer could e-mail the prescription to the e-druggist with no human involvement needed. The education of house staff is morphing into computer-search techniques. Surely this is a trend to watch.

Greenwald R. . . . And a Diagnostic Test Was Performed. *N Engl J Med* 2005; 353:2089-2090.

BUT DOCTORS USE GOOGLE TOO

A Wolters-Kluwer survey asked ~300 AMA member physicians: "*How often do you use the following sources to gain information used to diagnose, treat, and care for patients?*"

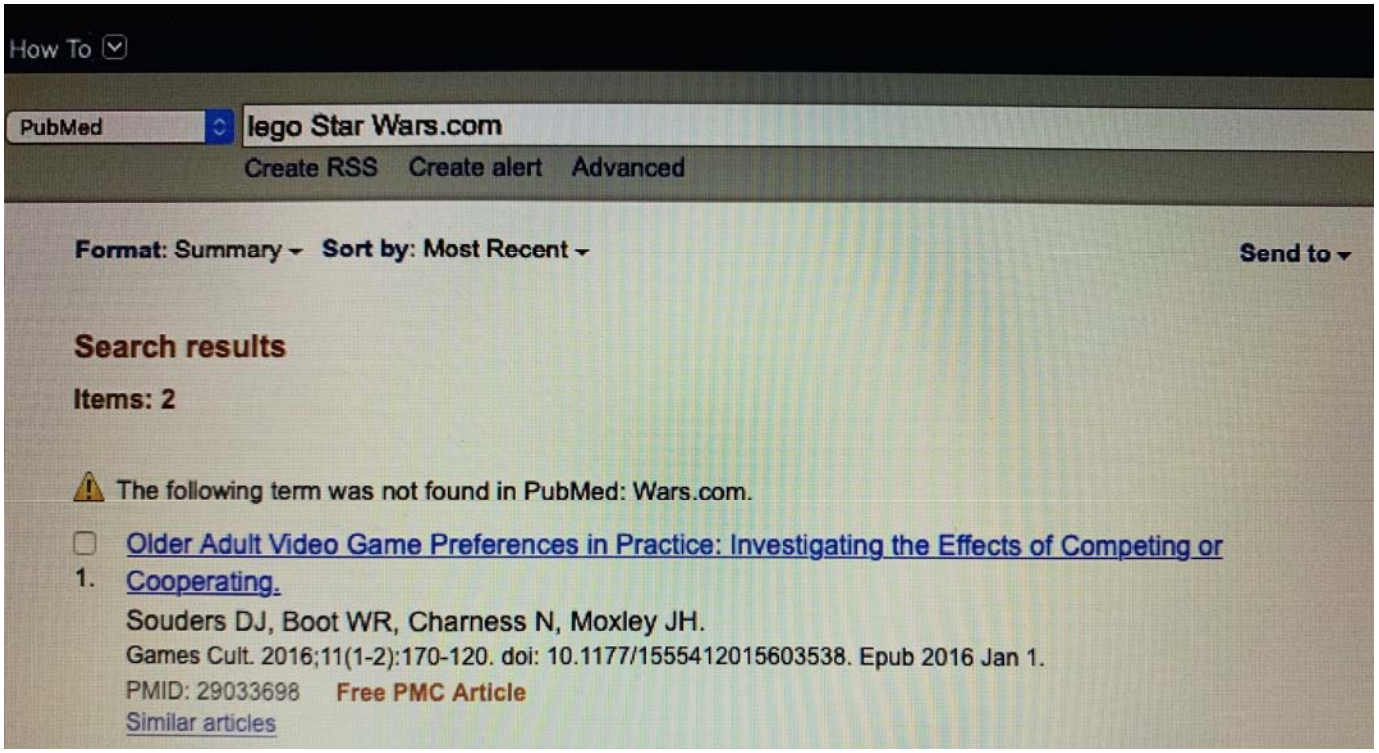


http://wolterskluwer.com/binaries/content/assets/wk-health/pdf/company/newsroom/white-papers/wolters-kluwer-health-survey-executive-summary-media.pdf

PUBMED

- Publicly available since June 1997
- Evolved from:
  - Index Medicus – a monthly guide to medical articles maintained since 1879 by the National Library of Medicine
  - Medical Literature Analysis and Retrieval Systems (MEDLARS) – launched in 1964 and was the first large-scale computer-based retrospective search service available to the general public
  - MEDLINE = MEDLARS Online; organized by Medical Subject Headings (MeSH), including publication type
- Primary user community is professional

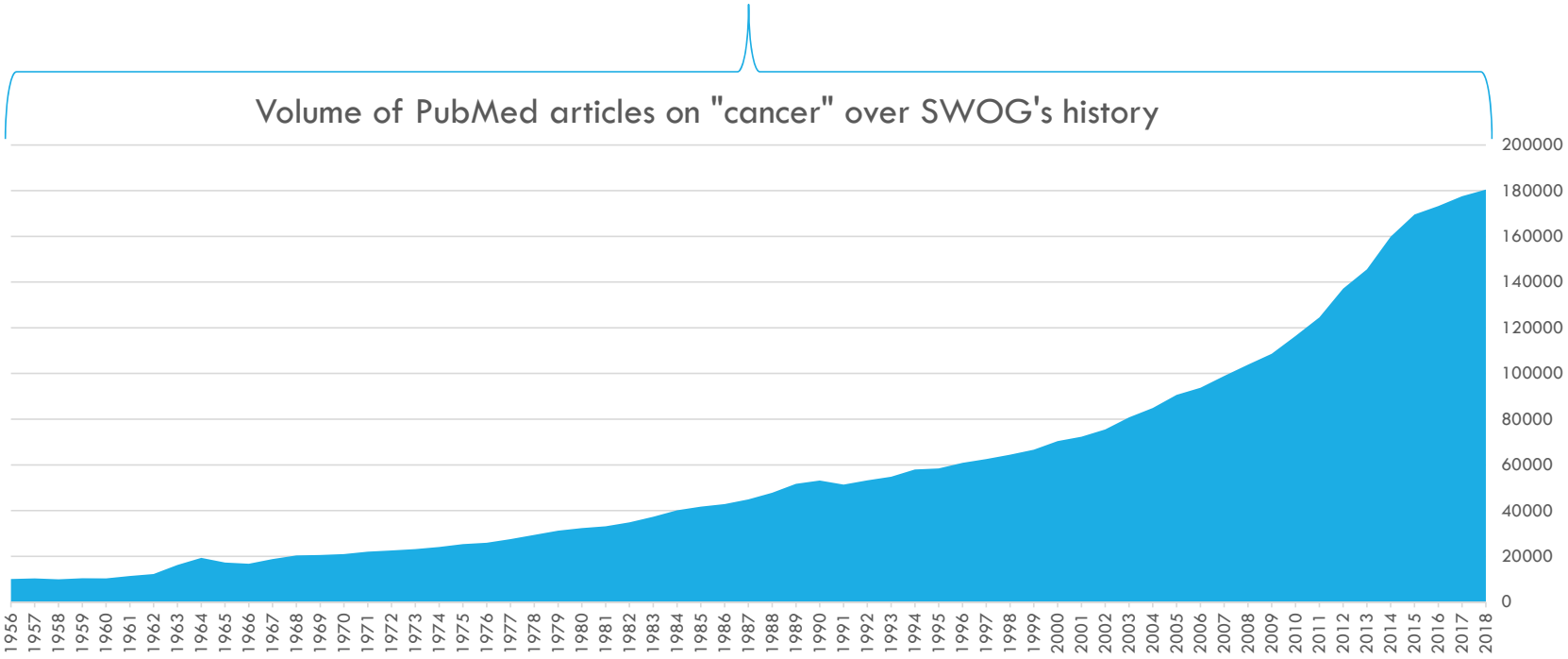
NOT A SEARCH ENGINE OPTIMIZED FOR EVERYONE



Yoo I, Mosa AS. Analysis of PubMed User Sessions Using a Full-Day PubMed Query Log: A Comparison of Experienced and Non-experienced PubMed Users. *JMIR Med Inform*. 2015 Jul 2;3(3):e25

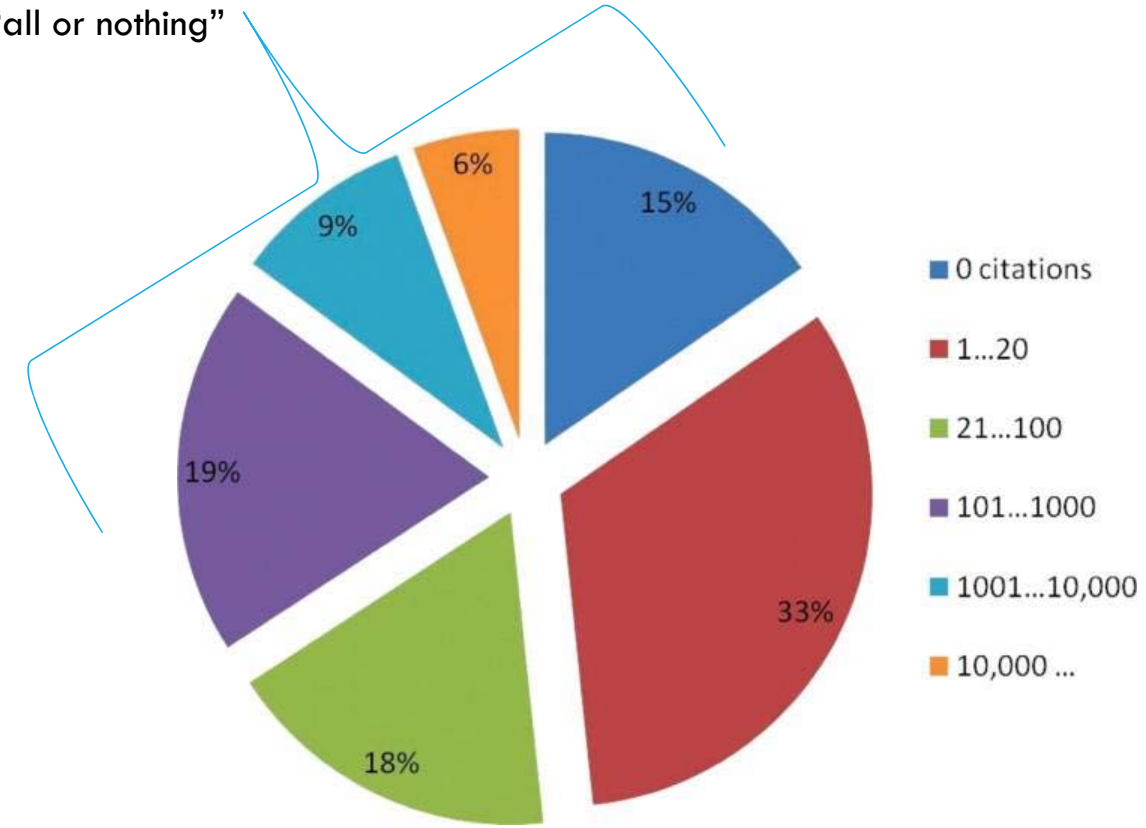
THE RISING TIDE OF INFORMATION

4.6 million articles in total!



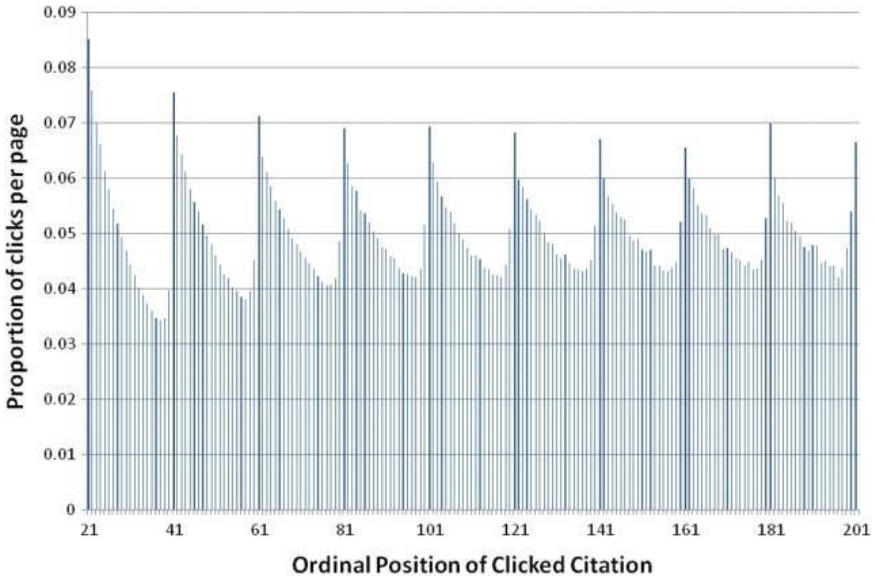
CITATION YIELD FROM PUBMED SEARCHES

Half are “all or nothing”



TRENDS IN PUBMED USAGE

- Over 80% of users only browse and click results on the first page (~30% on the top ranked citation)
- Clickthrough from abstract to full text is ~30%
- Over 20% of PubMed usage now occurs on mobile platforms



Dogan RI, Murray GC, Névéol A, Lu Z. Understanding PubMed® user search behavior through log analysis. *Database (Oxford)*. 2009, Nov 27.

DISCERNMENT IN THE DELUGE

"Some people have questioned the role of medical journals in this age of easy access to information. We think that, on the contrary, easy access to unvetted information … [makes] the journals' work more valuable, not less. **With so much medical content available on the Internet and with more accumulating every day, no one can keep up with the flood of ideas and data.**

What health professionals want and need is a trusted information source that can winnow the key kernels of new clinical information from the mountains of associated chaff."

Drazen JM. "Thank You." *N Engl J* Med. 2019 Sept 5; 381(10): 978.

UP TO DATE

Founded in 1992 by Dr. Burton Rose, beginning as the electronic conversion of a nephrology textbook he had authored

Content experts author review articles that are iteratively updated

1,000,000 topics viewed daily, with estimates of 30% change upon decision-making per view

Intended to be a point-of-care resource, with deliberately concise recommendations made to guide treatment

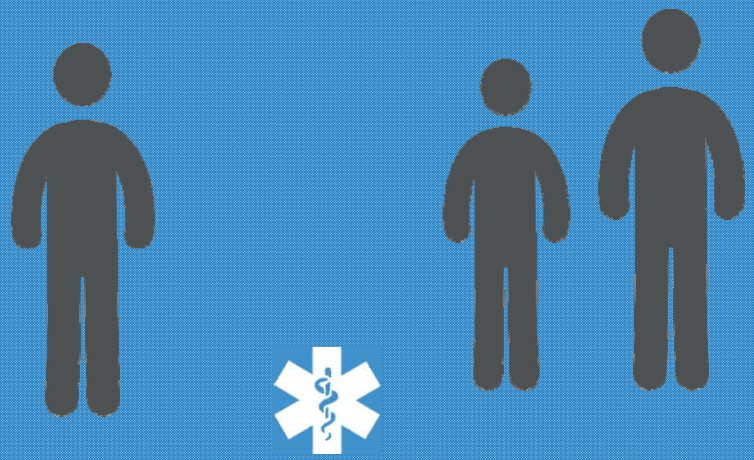
STRONG VS. WEAK

- A 2017 analysis found 9451 GRADEs within UpToDate across 2971 topics (of which 475 were oncologic in subject matter)
- **The majority of recommendations on UpToDate are weak (6501, 68.8%)**
- Of strong recommendations, the majority are based on at best moderate certainty of effect estimates
- Discordance between strength of recommendation and magnitude of benefit may be warranted in cases where there is surety about the cost/harm of an alternative
- Narrative presentation of recommendations results in a free text structure where explicit risk/benefit analyses and even citations might be omitted

Agoritsas T, Merglen A, Heen AF, Kristiansen A, Neumann I, Brito JP, Brignardello-Petersen R, Alexander PE, Rind DM, Vandvik PO, Guyatt GH. UpToDate adherence to GRADE criteria for strong recommendations: an analytical survey. *BMJ Open*. 2017 Nov 16;7(11):e018593.

The Traditional Process: Phone a friend

ASK COLLEAGUES AND EXPERTS QUESTIONS IN HOSPITAL HALLWAYS, ON THE PHONE, VIA EMAIL



Problems with this:

1) The value of knowledge exchanged depends on the your network

2) Valuable experiential knowledge from strong networks are not documented and shared with the community.

Slide courtesy of Dr. Nadine Housri, TheMedNet

the mednet

Search Questions, Topics or People

Most Recent | Unanswered Questions

What is a safe and effective dose and fractionation for palliating the head and neck primary?

I have a patient with metastatic NSCLC and a concurrent head and neck primary.

New answer August 4, 2016

Many responders have commented on Quad Shot. I'd like to add to ...

Manuj Agarwal, Wexner Medical Center at The Ohio State University

Unfollow Question · Follow User · 8 Answers available

In what situations do you consider adjuvant radiation for ovarian cancer?

For example, would you consider adjuvant chemotherapy alone to be sufficient in a patient with an isolated p recurrence and positive margin after...

New answer July 29, 2016

Our understanding of the role of RT in ovarian cancer has been evolvin...

Patricia Eifel, University of Texas MD Anderson Cancer Center

Unfollow Question · Follow User · 2 Answers available

Off trial, do you offer hypofractionated courses of radiation with temozolomide for "elderly" patients with GBM?

Does the MGMT status change your decision-making? Should we be routinely testing MGMT for elderly patie

New answer July 26, 2016

Yes, we do offer hypofractionated RT for elderly GBM patients off tria...

Tony Wang, Columbia University Medical Center

Unfollow Question · Follow User · 3 Answers available

How long should one wait before biopsying a persistently palpable mass of early st nodular lymphocte predominant Hodgkin lymphoma (NLPHL) after radiation?

In other words, how long after radiation therapy do you expect the palpable mass to completely resolve?

the mednet

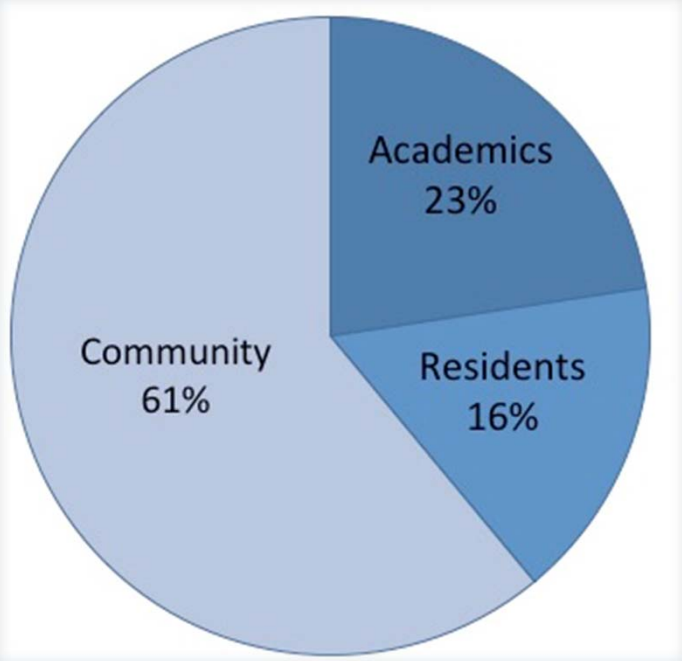
BRING THE EXISTING Q&A PROCESS IN MEDICINE ONLINE

GIVE CLINICIANS ACCESS TO STRONG EXPERT NETWORKS

Slide courtesy of Dr. Nadine Housri, TheMedNet

THE MEDNET COMMUNITY HAS GROWN TO OVER 9,300 ONCOLOGISTS

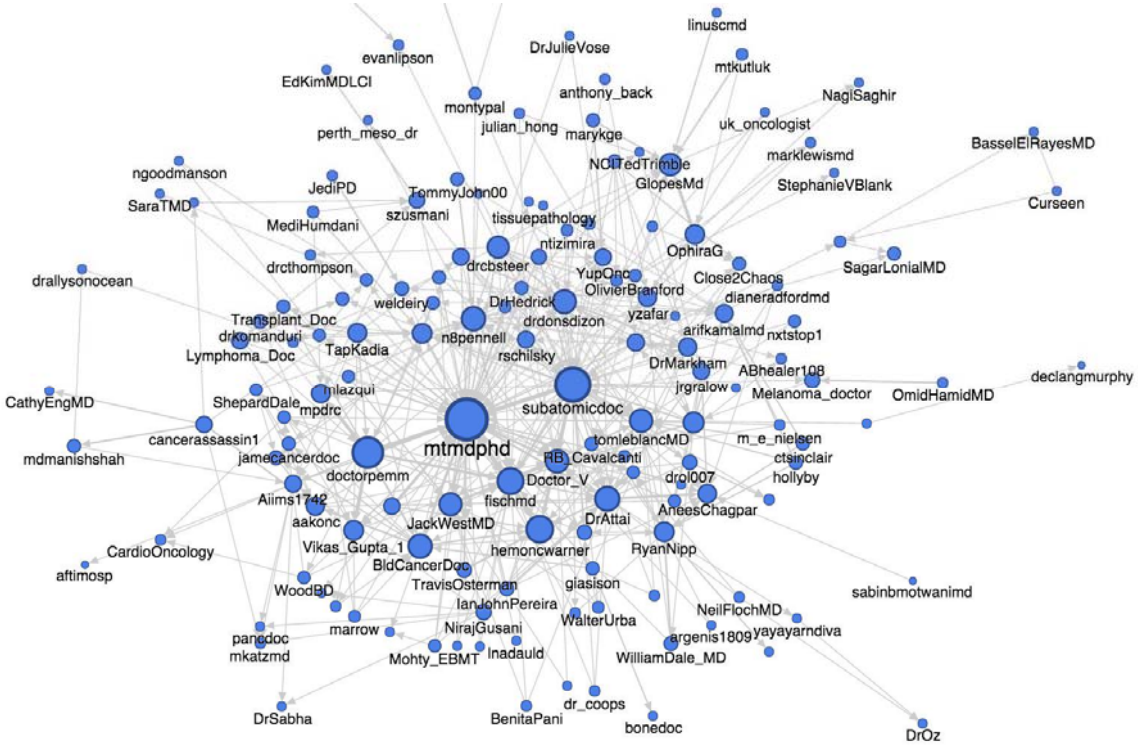
- > 90% of all US Radiation Oncologists from over 700 institutions
- > 35% US Medical Oncologists
- > 30% US Gynecologic Oncologists
- 500+ academic oncologists from every major cancer center have answered questions



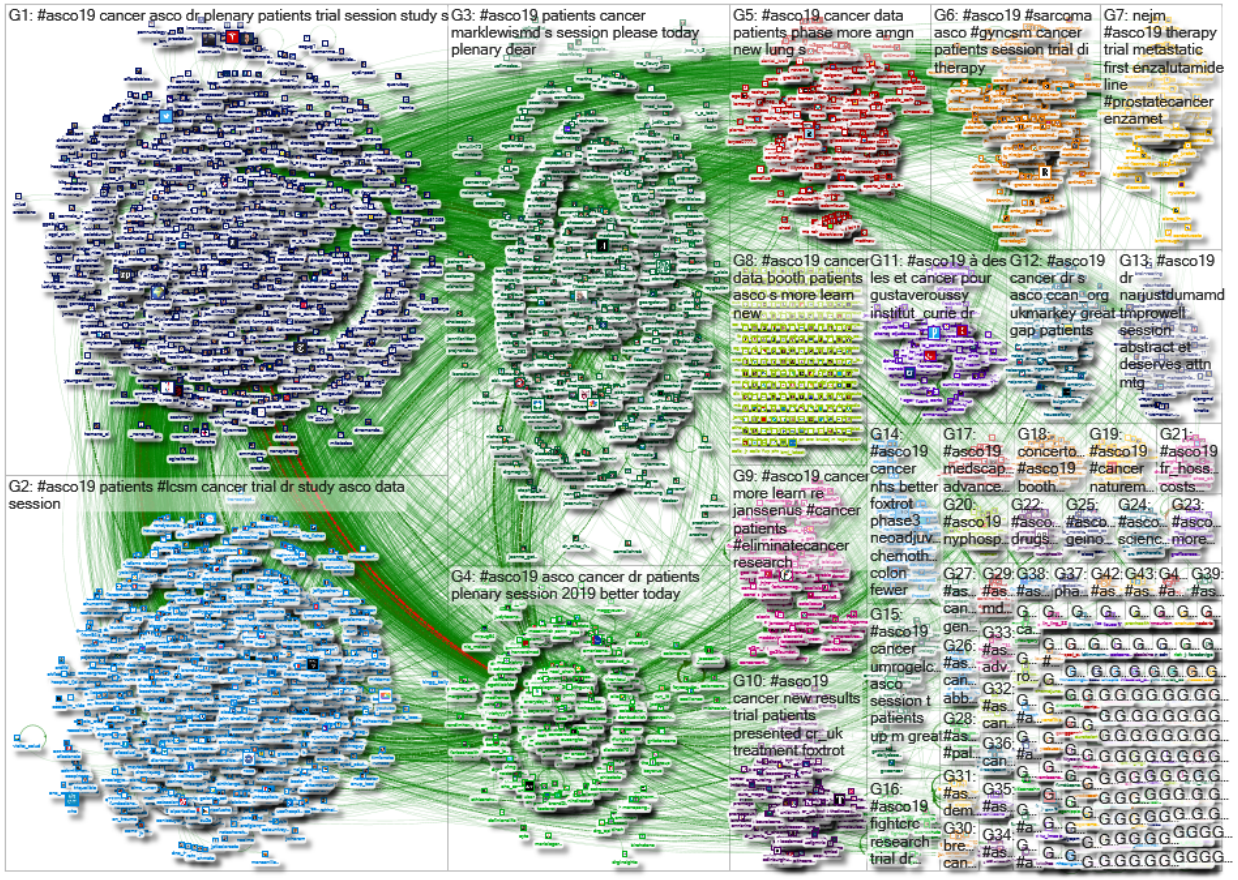
Slide courtesy of Dr. Nadine Housri, TheMedNet

TWITTER

- Currently the dominant digital platform for MDs to engage one another and the public
- Means of curation and contribution
- Virtual conference attendance



VISUALIZING EXCHANGES AT MEETINGS



HASHTAG ONTOLOGY

Table. Hashtags in the Cancer Tag Ontology

Hashtag	Disease
#adcsm	Adrenal cancer
#ancsm	Anal cancer
#ayacsm	Adolescent and young adult cancer
#bcsm	Breast cancer
#blcsm	Bladder cancer
#btsm	Brain tumors
#crcsm	Colorectal cancer
#esocsm	Esophageal cancer
#gyncsm	Gynecologic cancer
#hncsm	Head and neck cancer
#hpbcsm	Hepatobiliary cancer
#kcsm	Kidney cancer
#lcsm	Lung cancer
#leusm	Leukemia
#lymsm	Lymphoma
#melsm	Melanoma
#mmsm	Multiple myeloma
#pancsm	Pancreatic cancer
#pcsm	Prostate cancer
#pedcsm	Pediatric cancer
#scmsm	Sarcoma
#stcsm	Stomach cancer
#thmsm	Thymoma & thymic carcinoma
#thycsm	Thyroid cancer
#tscsm	Testicular cancer

Breast cancer advocates had started breast cancer social media (#bcsm) in 2011

Brain tumor social media (#btsm) followed in 2012

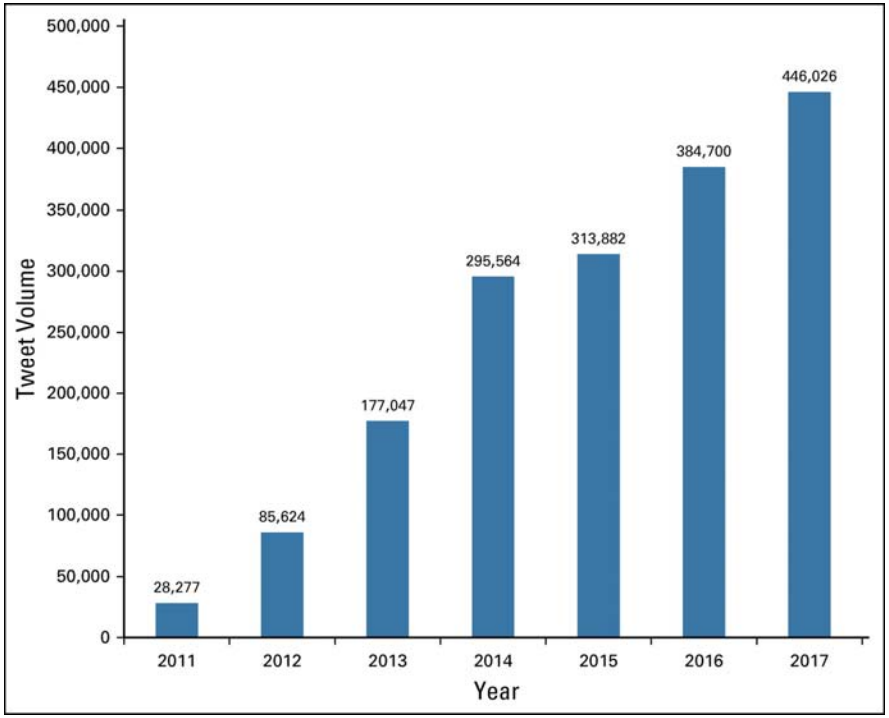
Following those organic examples, another 23 hashtags were developed with the following criteria:

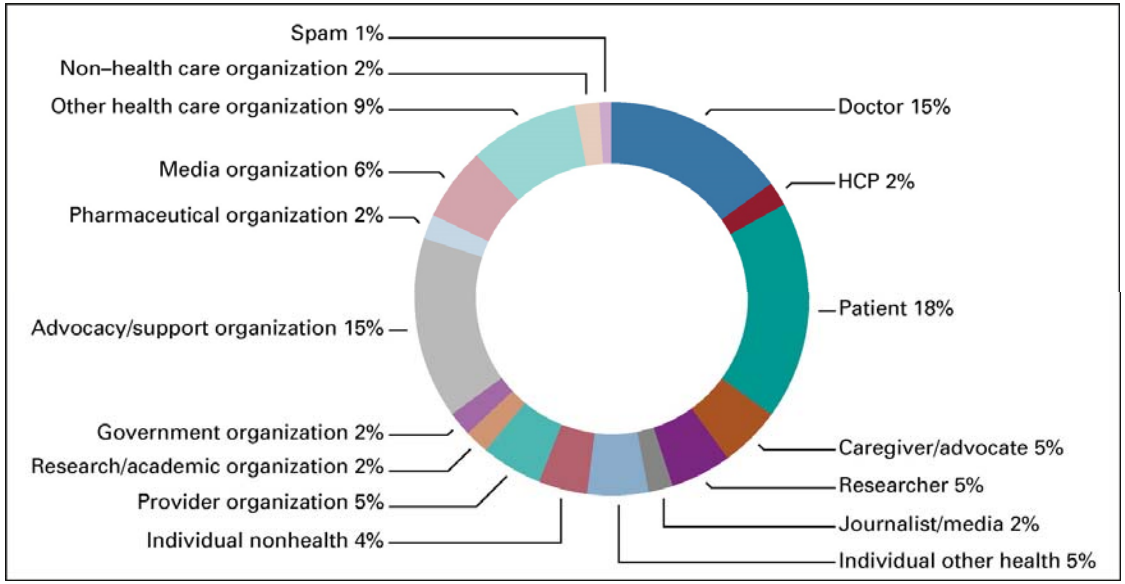
- disease-specific
- short, unique, or minimally used on Twitter
- ending in “sm” for “social media” (as a prompt that online use is public)

Attai DJ, Cowher MS, Al-Hamadani M, Schoger JM, Staley AC, Landercasper J. Twitter Social Media is an Effective Tool for Breast Cancer Patient Education and Support: Patient-Reported Outcomes by Survey. J Med Internet Res. 2015 Jul 30;17(7):e188.

Katz MS, Anderson PF, Thompson MA, Salmi L, Freeman-Daily J, Utengen A, Dizon DS, Blotner C, Cooke DT, Sparacio D, Staley AC, Fisch MJ, Young C, Attai DJ.
Organizing Online Health Content: Developing Hashtag Collections for Healthier Internet-Based People and Communities.
JCO Clin Cancer Inform. 2019 Jun;3:1-10.

HASHTAG UPTAKE





Katz MS, Anderson PF, Thompson MA, Salmi L, Freeman-Daily J, Utengen A, Dizon DS, Blotner C, Cooke DT, Sparacio D, Staley AC, Fisch MJ, Young C, Attai DJ.
Organizing Online Health Content: Developing Hashtag Collections for Healthier Internet-Based People and Communities.
JCO Clin Cancer Inform. 2019 Jun;3:1-10.

CROWDSOURCING THIS TALK!

Mark Lewis
@marklewismd

To my fellow patients, what are your go-to digital resources for health information?

Asking to prepare a @SWOG talk on how we can curate online resources for maximum reliability and better engage those under our care & considering clinical trials.

Thanks in advance!
#swogonc

Alicia C. Staley
@stales

Replying to @marklewismd and @SWOG

twitter is the search engine i use to surface the most timely resources. Look for ways to curate and uncover right info at the right time. impossible to curate a list of static sources. it's about methodologies to FIND info

Enlightening Results
@GraceCordovano

Replying to @marklewismd and @SWOG

👉UptoDate
👉NCCN patient guidelines
👉@twitter hashtags: disease specific, keyword, tweetchats
👉 healthcarebluebook.com/ui/consumerfro...
👉@GoodRx
👉@NationalPOLST
👉@CoalitionCCC for #PalliativeCare & #EoL Resources
👉@savvy_coop for gigs for patients to share their expertise 🎯

HOW OUR PATIENTS ENGAGE DIGITALLY

- 97% use the Internet to search for information about cancer
- 94% search on Google
- Results yielded:
  - Most accurate about etiology (70%) and symptoms (67%)
  - Least accurate about prevention (55%), treatment (55%), and prognosis (43%)
  - Tradeoffs between readability and reliability
  - Patients with rarer cancers are particularly vulnerable to the surfacing of misinformation
  - Searching about specific medications leads to pharmaceutical websites ~20% of the time

Chang K, Berthelet E, Grubbs E, Hamilton S, Karvat A, Tran E, Wu J, Ingledew PA. Websites, Websites Everywhere: How Thyroid Cancer Patients Use the Internet. *J Cancer Educ*. 2019 Jul 22.

De Groot L, Harris I, Regehr G, Tekian A, Ingledew PA. Quality of Online Resources for Pancreatic Cancer Patients. *J Cancer Educ*. 2019 Apr;34(2):223-228

Kuenzel U, Monga Sindeu T, Schroth S, Huebner J, Herth N. Evaluation of the Quality of Online Information for Patients with Rare Cancers: Thyroid Cancer. *J Cancer Educ*. 2018 Oct;33(5):960-966.

Beaton C, Codd RJ, Holland PA, Gateley CA. Evaluation of the quality and accuracy of information regarding aromatase inhibitors available on the internet. *Breast J*. 2008 Jul-Aug;14(4):366-8.

Grewal P, Alagaratnam S. The quality and readability of colorectal cancer information on the internet. *Int J Surg*. 2013;11(5):410-3

Google

- Launched September 1998
- By August 1999, one billion searches per year were performed via Google
- By 2000, more than half of Google users had searched for health information at least once
- As of 2019, more than two trillion annual searches were performed, of which 7% were health-related, amounting to ~70,000 such queries per minute
- Health-related searches double in the weeks before a patient's ER visit, and ~50% of patients who use Google in the week prior to presentation search for content directly related to their chief complaint

Asch JM, Asch DA, Klinger EV, Marks J, Sadek N, Merchant RM.
Google search histories of patients presenting to an emergency department: an observational study.
BMJ Open. 2019 Feb 20;9(2).

SEARCH ENGINE OPTIMIZATION?

PATIENTS VS. PAYWALLS

Rev. Dr. Stacey Simpson Duke @revdrduke · Sep 6
Replying to @marklewismd and @SWOG
1: PubMed
2: search of the footnotes of the articles I find via PubMed
(if/when I hit a **paywall**, I ask any friend in medicine or academics to access it for me)

A pastor with stage IV leiomyosarcoma

Ashley Farley @ashleydfarley
Replying to @mrgunn @dgmacarthur
People shouldn't have to jump through additional hoops to access information because they aren't privileged enough to be associated with an institution that can (nowadays its barely) afford subscriptions.

Associate Officer of Knowledge & Research Services at the Bill & Melinda Gates Foundation

mrgunn
@mrgunn

Yes, everyone should have rainbows, unicorns, & puppies delivered to their doorstep by volunteers. Y'all keep wishing for that, I'll keep working on producing the best knowledge and distributing it as best we can.

Elsevier's director of scholarly communications

Papadakos J, Trang A, Cyr AB, Abdelmutti N, Giuliani ME, Snow M, McCurdie T, Pulandiran M, Urowitz S, Wiljer D.
Deconstructing Cancer Patient Information Seeking in a Consumer Health Library Toward Developing a Virtual Information Consult for Cancer Patients and Their Caregivers: A Qualitative, Instrumental Case Study.
JMIR Cancer. 2017 May 24;3(1):e6.

A NON-BINARY APPROACH

The Lancet Oncology
@TheLancetOncol

Online now: CheckMate064-nivolumab then ipilimumab more beneficial, more tox vs reverse order in #melanoma ow.ly/GrCn300Ovt7 #ASCO16

Top 100 Altmetric ratings in 2018 included:

#8 – complementary medicine, refusal of conventional cancer therapy, and survival among patients with curable cancers [*JAMA Oncology*]

#16 – death or debt? National estimates of financial toxicity in persons with newly-diagnosed cancer [*American Journal of Medicine*]

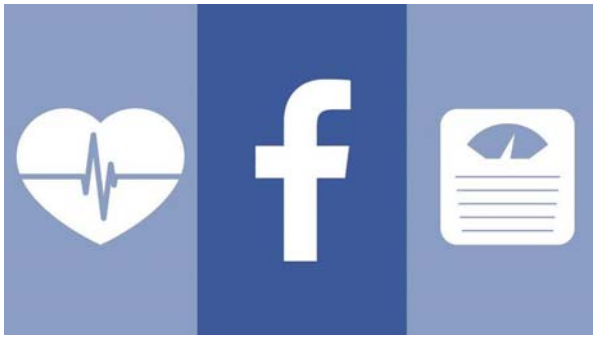
#22 – detection and localization of surgically resectable cancers with a multi-analyte blood test [*Science*]

#25 – association of frequency of organic food consumption with cancer risk [*JAMA Internal Medicine*]

#45 – adjuvant chemotherapy guided by a 21-gene expression assay in breast cancer [*NEJM, ASCO plenary*]

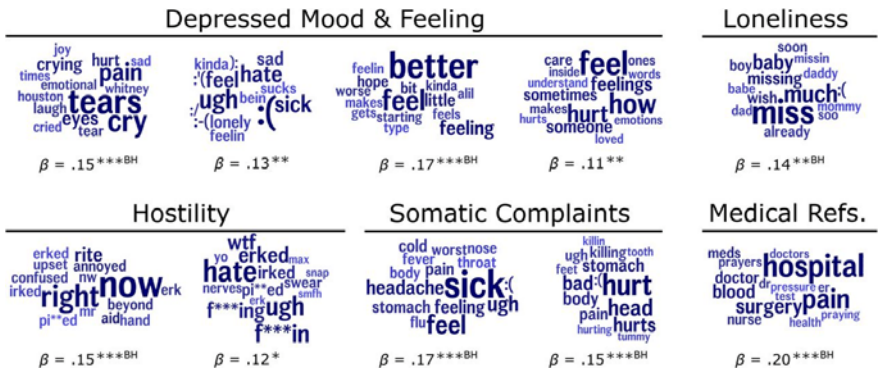
https://www.altmetric.com/top100/2018/

FACEBOOK



Of public posts, 7.5% are health-related

- In a study linking ER visits to social media posts, patients with a given diagnosis in the EMR were significantly more likely ($p<.0008$) to use terms related to that condition on Facebook
- Patients self-disclose signals about their mental & physical health



<1% of posts concern clinical trials and research studies

Padrez KA, Ungar L, Schwartz HA, Smith RJ, Hill S, Antanavicius T, Brown DM, Crutchley P, Asch DA, Merchant RM. Linking social media and medical record data: a study of adults presenting to an academic, urban emergency department. *BMJ Qual Saf*. 2016 Jun;25(6):414-23.

Eichstaedt JC, Smith RJ, Merchant RM, Ungar LH, Crutchley P, Preoțiuc-Pietro D, Asch DA, Schwartz HA. Facebook language predicts depression in medical records. *Proc Natl Acad Sci U S A*. 2018 Oct 30;115(44):11203-11208.

“DESTINY SHARING” IN GROUPS

For Health Communities, Facebook is Too Important to Delete

Social Media and SWOG:

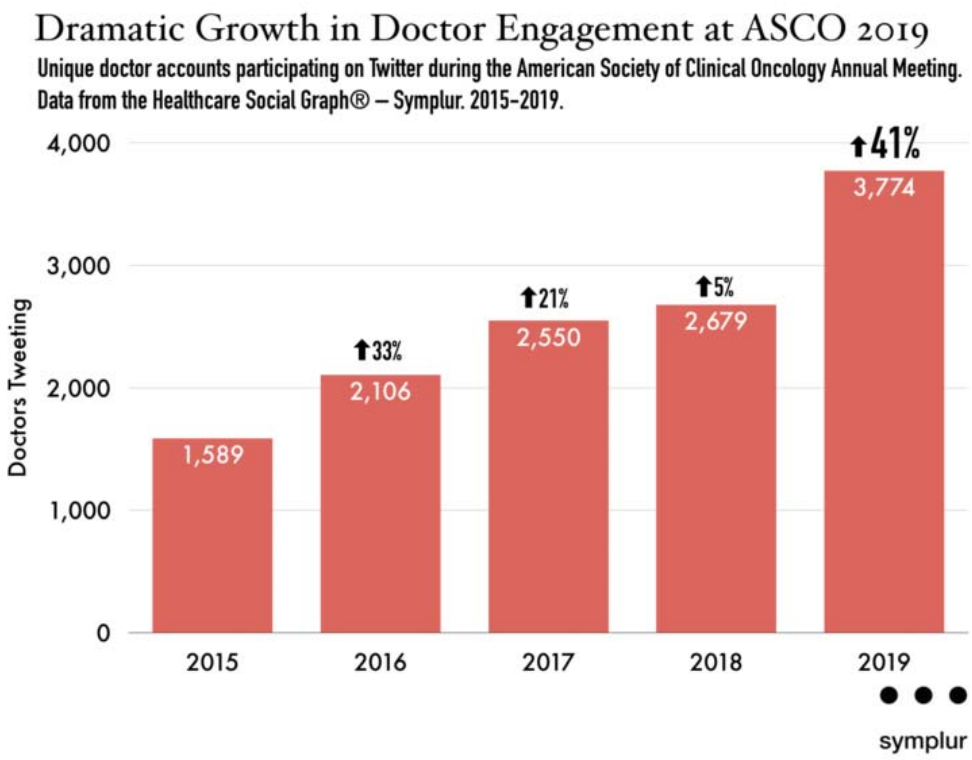
Using it to enhance clinical trial development, conduct, and dissemination

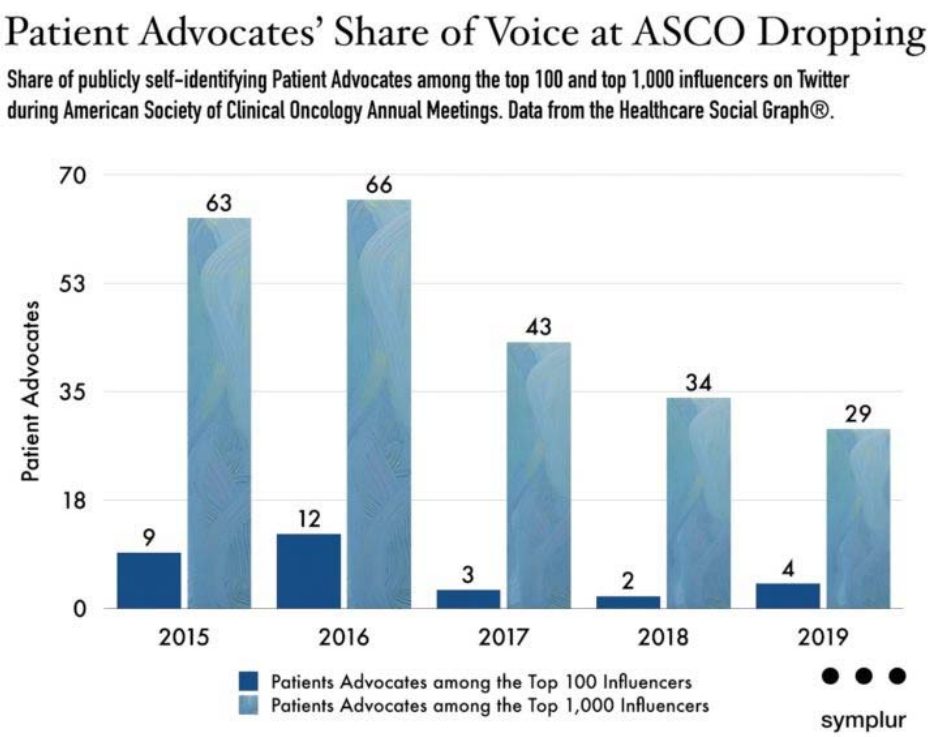
Michael J. Fisch, MD MPH

The University of Texas MD Anderson Cancer Center

SWOG Plenary: May 4, 2013

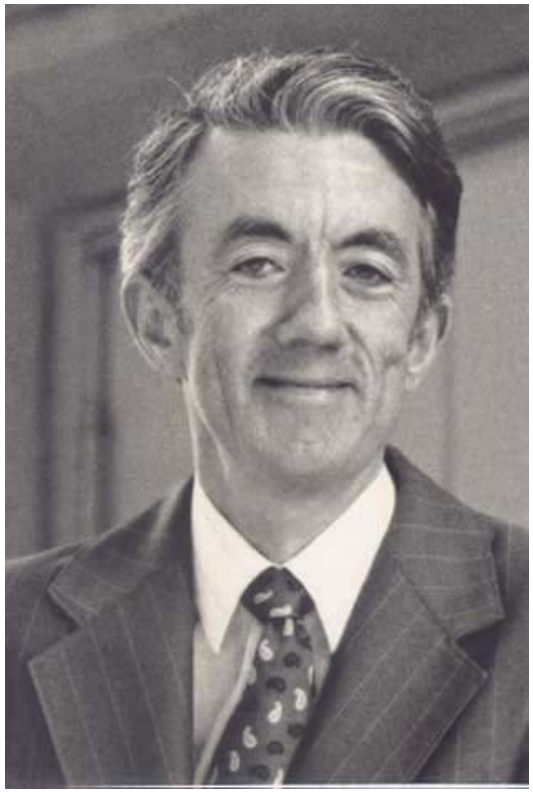
THE SHIFTING PROPORTION OF "VOICES" ON TWTTER AROUND ASCO ANNUAL MEETINGS

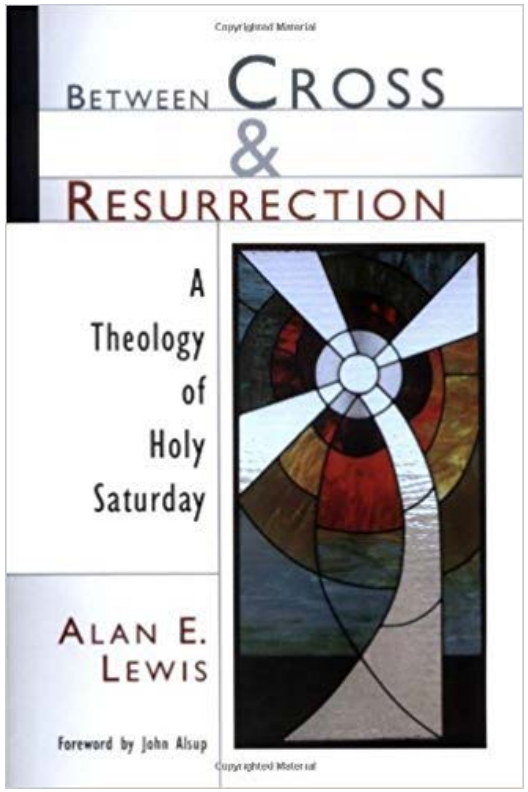




WE CANNOT TAKE OUR ADVOCATES FOR GRANTED

A QUARTER-CENTURY OF PROGRESS





THIS IS WATER