CONSUMER UNDERSTANDING OF LABORATORY TESTING
– LAB TESTS ONLINE
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Objectives

Recognize how patient-centered care impacts consumer-driven laboratory testing
Outline how health literacy and medical knowledge impact consumers' understanding of laboratory testing
Extrapolate how Lab Tests Online information may relate to consumer-driven testing
Patient Centered Healthcare

Patient Active Participation in Healthcare

Care that involves patients in making informed medical decisions

Requires patient and physician to have common level of communication

Requires patient to have a certain level of health literacy
Patient Centered Healthcare

Benefits

Research shows that patient-centered healthcare is associated with

• Increased patient satisfaction and compliance
• Better health outcomes
• Reduced healthcare costs
Patient Centered Healthcare

Direct to Consumer Testing

The growing interest in and marketing of laboratory tests to consumers would seem to facilitate patient centered healthcare

Allowing individuals to order their own laboratory tests removes barriers to access of test results

A major challenge with this approach is how well lay public can interpret the results they are given
Patient Centered Healthcare

Direct to Consumer Testing

Patients aren't required to review the results with physicians

According to a survey reported in the *Annals of Internal Medicine* (2016;164:513), nearly two-thirds of people who bought DTC genetic tests said they planned to share the results with their healthcare practitioner, but after 6 months only 27% had actually done so.
Health Literacy

The ability to read, understand, and act on health information

Most need help interpreting health information

Most health care materials are written at 10\textsuperscript{th} grade reading level

Average American reads at 8\textsuperscript{th}-9\textsuperscript{th} grade level, and 20\% at 5\textsuperscript{th} grade or below
Health Literacy

Consequences of Impaired Health Literacy

In studies, literacy skills are a stronger predictor of health status than age, income, employment status, education level, or racial/ethnic group.

In US, almost 1/3 of population estimated to have problems understanding and acting on health care information.
Health Literacy

Consequences of Impaired Health Literacy

In studies, health literacy problems are associated with:

• Mismanagement of medications
• Failure to perform necessary follow-up visits and procedures
• Increased rates of hospitalization
• Increased morbidity and mortality
Health Literacy

Institute of Medicine Report 2004

US Institute of Medicine published “Prescription to End Confusion”

Described other issues in health literacy besides reading, including numeracy (ability to interpret numbers) and conceptual knowledge – both critical for laboratory tests
Health Literacy

Institute of Medicine Report 2004

Describe increased importance of self-management of health, which makes many demands on individual to process and act on information

Identified framework for health literacy improvement as well
Health Literacy

Points out that more than reading skills needed; requires:

• Background health knowledge
• Familiarity with health language
• Communication skills

Institute of Medicine Report 2004
Little research specifically related to testing

This despite the fact that laboratory tests are commonly performed on patients, and that they make up 60-70% of the objective information in physician’s notes.
Health Literacy on Lab Tests

Zarcadoolas C, NIH R21 CA133487-01A2 (Viewed Online)

- Studied small group using health portals; all computer literate, 75% home internet access, 57% smart phones
- “High interest in lab/test results, but reviewing results posed unusually high reading and numeracy demands – “If I could read it and understand it [I would use it] ... I can’t understand it.””
Health Literacy on Lab Tests

Zarcadoolas C, NIH R21 CA133487-01A2 (Viewed Online)

- Only half of patients could determine whether their results were “normal” or “abnormal” by reviewing data in an electronic medical record
- Many did not understand commonly used lab abbreviations
Health Literacy on Lab Tests

- Studied patients perceptions of understandability of items in electronic medical record; 81% reviewed test results
- Three most difficult to understand: 1) MD notes; 2) radiology reports; 3) lab reports (only 51% found easy to understand); 84% accessed the internet to help understanding
Health Literacy on Lab Tests

Sarkar J Health Commun 2010;15(s2):183

Studied self-reported health literacy and use of internet portal (including lab results) to help manage diabetes

62% reported health literacy problems; they were 40% less likely to use patient portal. Of the 69% who used portal, viewing lab tests was the most frequent use (76% of those accessing)
Health Literacy on Lab Tests

About 1/3 (34%) of patients still had unanswered questions about their tests after speaking to their doctor.

Almost 2/3 (61%) wanted better explanations of why blood tests were being done.

Over half (55%) had or planned to request specific tests from their doctor.

National Association of Chronic Disease Directors/Ortho Clinical Diagnostics
In light of the above points, direct to consumer testing provides additional challenges for those ordering their own tests.

Laboratory reports are typically data rich but information poor.

What resources could assist in facilitating use of direct to consumer laboratory results?
Lab Tests Online Vision

Inform Public on Importance of Lab Testing

Increase visibility of lab among Policymakers Medical professionals Students

Authoritative Informative

A public resource on clinical lab testing from the professionals who do the testing
Early History

• AACC’s HI5 patient education program launched (1999) – paper based patient education on 5 common laboratory tests (glucose, cholesterol, TSH, PSA, hemoglobin)
• Industry group recommends expanding HI5 to the web (2000)
• Initial editorial group selected with members from five partners (AACC, ACLA, ASCLS, ASM, CLMA), industry supporter agreements reached (Fall 2000)
• Project formally launched with hire of executive producer (Jan 2001)
Growing and Maturing

• US site now has over 300 test descriptions, over 100 condition descriptions, and adds a new news article about every 2 weeks

• Is updating over 100 articles/year; all updates are reviewed by science writers, at least 1-2 representatives of Editorial Board (and often full Board) for substantive edits and, once approved, these are made available to editors in all countries

• Editorial board continues to meet by conference call every 2 weeks, and performs a number of reviews of updated pages and news articles “off-line”
Social Media and Lab Tests Online

Expand content reach through Social Media, Newsletters, etc.
A global standard for patient education

By 2003, discussions with ACB led to a plan to develop a network of Lab Tests Online sites

- edited by national laboratory societies
- in which the sites support one another’s success by
  - working together to strengthen the brand
  - expanding and improving content
  - reaching more patients, families, and caregivers in their native languages
  - adapting content to local practices/guidelines/conditions
Globalizing Lab Tests Online

• 2004: UK version
• 2007: Spain, Germany, Poland, Australia, Hungary, Italy
• 2008: Greece, Czech Republic
• 2009: France, China
• 2010: Portugal, Brazil
• 2011: Turkey
• 2012: Korea, Romania

By end 2012: 14 languages, 17 countries
Growth Milestones

- Lab Tests Online-US launched July 31, 2001
  - 1 millionth visitor - July 2002
  - 10 millionth visitor - February 2005
  - 25 millionth visitor - October 2006
  - 50 millionth visitor - September 2008
  - 100 millionth visitor – March 2011
  - 200 millionth visitor – March 2015
  - On pace to reach 300 millionth visitor in early 2017
  - Currently #65 in traffic among health sites (Alexa)
World-Wide User Traffic

• 2009, 10 sites, total 23.2 million, average 1.93 million/month
• 2011, 15 sites, total 30.6 million, average 2.5 million/month (switched analytic tool, reports about 20% less; corrected, 20% up from 2010)
• 2012, 16 sites, total 27.0 million, average 2.3 million/month
• 2015, 17 sites, 41.9 million, average 3.5 million/month
• July 2016 YTD, 17 sites, 27.9 million, average 3.9 million/month
As conceived, intended to provide information for patients seeking to review their laboratory test results before and/or after speaking with their healthcare practitioner; not initially envisioned as a resource for those who self-ordered laboratory tests.

Patients who order DTC tests can use LTO to better understand their lab tests and the implications of results but are encouraged to discuss any health concerns with their providers and to consider making appointments to follow up on lab test results.
What Is Included

Test articles (n=337) – Description of test, what results mean, other information, FAQ’s, references, links to useful sites

Condition articles (n=129) – Description of disease(s), diagnostic and other tests used, references, links
Lab Tests Online

What Is Included

Screening articles (n=18) – Recommended screening tests for individuals of different ages, prenatal and neonatal screening

Feature articles (n=22) – More information about aspects of laboratory testing such as reference intervals, obtaining samples, genetic testing, limited information on methodology, annotated sample lab reports
What Is NOT Included

Reference intervals for most tests – link to feature on reference intervals explaining why test results may vary between labs

Differential diagnosis for causes of abnormal lab results

Information on most common interferences
Patient Feedback

“I was getting very frustrated trying to find info on thyroglobulins. I tried to find this info in an endocrine website and your website had far more information than that medical one. I found exactly what I was looking for. Thank you.”

“I have used your site many times and referred others to it many times. I thought it was past time that I commend you for this WONDERFUL and immensely empowering site.... Thank you for being a valuable part of my informational resources!!”

“Your site is EXACTLY what I was looking for. It gave me ALL the information necessary to understand each test in my Total Work Up. I had questions on some, and you perfectly explained in a manner anyone could understand. I understood EVERYTHING without ANY trouble. I am SO Happy to have found you!! Your site is THE BEST! Thank you for being there.”
Patient Feedback

“I have never seen a website that explains things as plainly and simple and yet rich in information...keep up your excellent job.”

“A tip of the hat for a wonderfully informative Web Page! The amount of detailed information is absolutely perfect. It appears to be designed with the non-medical profession in mind. In other words, understandable terminology!”
“The information provided has been so very helpful in my work as an investigator in a health related regulatory agency. It has also been very helpful in care of my patients and for friends and family. It is a very comprehensive, useful and friendly site. It offers great information at all levels of understanding.”

“I just want to take a moment and thank you for maintaining this invaluable source of information. I refer MS patients on medhelp.org to your site all the time when they have questions about test results. Thanks again!”

“Excellent, Excellent, Excellent!!! I also appreciate the clear and concise summaries on medical conditions. Its often better explained than my medical text books.”
Media Endorsements & Mentions

One of the Smartest Health Sites on the Web
--Prevention magazine

Rely on trusted sources for information about lab tests...... such as Lab Tests Online.
--Scientific American

... a masterfully simple page ...  
--Washington Post

One of the best medical sites online
--NBC TV

... a useful resource that offers reliable information ...
--U.S. News & World Report

Lab Tests Online..was developed by lab professionals to help patients &providers navigate the nuances of testing.
--The Wall Street Journal
LTO-App

• US version launched in July 2011 on Apple iOS and Google Android; currently about 20,000 users

• Automatically draws content from server first time connected to internet, and subsequently each time internet accessed

• Now also available for UK (15,000 users), Australia (14,000); targeted to medical students, health professionals
Moving Forward

**Continued growth in use by Medical Professionals**
- Example – Australia outreach to medical students with new App
- Example – Brazil outreach to universities to promote lab medicine and LTO
- Example – UK find med students as a captive audience for LTO given the lack of lab training in medical school
- Example – US enhancing Healthcare Practitioner pages on website to attract and engage more medical professionals

**New Redesign**
- Increased engagement: e.g. More interactive media
- Mobile Friendly
- Improved search
- Enhanced user experience

**New Country Site Interest - Egypt (Arabic Site)**
SUMMARY

• Lab Tests Online is a unique example of delivering health literacy content on an international scale

• It continues to expand and grow in usage in most countries, and is a top 100 health-related web site

• Currently in redesign phase to optimize user experience, especially for mobile device users
SUMMARY

• Content is available for use by those choosing to order laboratory tests on themselves
• Content has been licensed by some laboratories (such as Theranos) to use as part of their direct-to-consumer marketing
• Currently, no specific information available on how well it meets this particular need