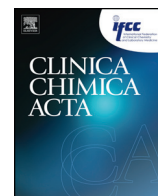




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Lab Tests Online and consumer understanding of laboratory testing

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ABSTRACT

Lab Tests Online is a “peer-reviewed, non-commercial, patient-centered” resource where patients and their relatives and caregivers can learn about the tests used to screen for, diagnose, and manage disease. Consumers are becoming increasingly involved in the management of their own health care and increasingly have access to their laboratory results through electronic health records. Research has shown that consumers have difficulty with health literacy in general and with numerical data in particular. The Lab Tests Online global websites are an important step toward helping consumers understand the complexity of the pathology process, the expertise of the people involved and the meaning of the results provided to them and their healthcare professionals.

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1. Introduction

Lab Tests Online was launched in the United States in 2001 as a “peer-reviewed, non-commercial, patient-centered” resource where patients and their relatives and caregivers can learn about the tests used to screen for, diagnose, and manage disease. In the same year, the Institute of Medicine (IOM) described its vision for healthcare in the new century. It defined “patient-centered care” in a way that makes patients – including their preferences, needs, and values – be an integral part to decision-making regarding their own health [1]. In order for patients to take on that central role in decision-making, it is essential that they develop a greater understanding of all facets of their care, including laboratory medicine.

Lab Tests Online delivers detailed descriptions of hundreds of tests, condition descriptions that are cross-referenced by related tests, recommendations on preventive screening from leading authorities, news summaries tracking the latest advances in testing that affect the healthcare consumer and in-depth articles on such topics as the meaning of reference intervals, accuracy and precision in testing and how laboratories work. Lab Tests Online provides all of these to the user with the promise that the content has been reviewed and approved by the professionals who do the testing.

Created and produced by the American Association for Clinical Chemistry (AACC), originally in collaboration with the American Society

for Clinical Laboratory Science, the American Society for Microbiology, the Clinical Laboratory Management Association, and the American Clinical Laboratory Association, the website now benefits from the expertise of 17 laboratory professional societies and associations that have partnered to develop the content for the site. The original US site is supported by corporate sponsorships and fees derived from licensing content to third party websites.

Traffic to the US website has grown steadily in the 12 years since it was launched, with the one millionth visit occurring 14 months after the launch, and the 100 millionth visit occurring in its 10th year online. In 2013 the site averages about 2 million visits a month and recently celebrated its 150 millionth visitor. The site hosted more than 26 million visitors in 2012.

AACC's counterparts around the world became interested in adapting the website to serve people in their own countries and in their own language. In 2004, the Association for Clinical Biochemistry became the first organization to launch a version of the website adapted to the local policy, practice and language in the United Kingdom. Over the next eight years, versions of Lab Tests Online were launched in Spain (2007), Germany (2007), Poland (2007), Australia (2007), Hungary (2007), Italy (2007), Greece (2008), Czech Republic (2008), People's Republic of China (2009), France (2009), Brazil (2010), Portugal (2010), Turkey (2011), the Republic of Korea (2012), and Romania (2012). These global sites combined to attract almost seven million visitors in 2012.

Funding and operational models for the Lab Tests Online sites differ according to the country in which the site operates. The UK site was initially funded by an independent charitable body, after that by the

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UK government and is currently funded by laboratory medicine professional bodies. The Australian site continues to be funded by grants from the Australian government, while those on the European continent are funded through industry associations. How content is translated and adapted in each country varies as well, but in all cases the process is overseen by one or more editors from the lead laboratory association, who approve the final content that appears on the live website. The number of localized articles available on each site also varies and is dependent on the editorial resources within the country available to the lead association. The ability of each editorial team to regularly review and update the content on the site is another factor that may limit the volume of content that is localized.

New content is generated mostly in the United States, but some new articles have been drafted by the editorial teams in Australia and the UK. All new and updated contents are shared across the global network of sites.

2. Health literacy

Health literacy is the ability of consumers of health care to read, understand, and act on health care information. Health literacy is a major determinant of outcomes of health care interactions between a patient and their health care team. A major research study of health literacy in American adults, done in 2003 [2], found that 36% of adults had inadequate health literacy, while only 12% would be considered proficient. They also found that poor health literacy was not limited to those with inadequate literacy skills in general, but even among high school graduates many had health care literacy issues. The IOM published an extensive review of the issue of health literacy in 2004 [3]. They point out that the increasing reliance on self-management in treating many diseases requires patients to be able to understand health care information and act on that information to effectively manage their disease process. At the same time, there is a significant mismatch between the level of information and patient's ability to utilize that information to effectively manage their care.

Health literacy involves a number of skills beyond simple reading comprehension; with respect to laboratory tests, an important component of literacy is numeracy, the ability to read and interpret numerical information. In a systematic review of health literacy research and its impact on health outcomes, the United States Agency for Health Care Research and Quality (AHRQ) found inadequate information on numeracy skills and their relation to health care outcome [4]; however, in four studies that it reviewed, numeracy skills were more strongly correlated to health outcomes than was overall health literacy. People with limited literacy have worse outcomes when affected by diseases that require significant participation in disease management (including diabetes, dyslipidemia, obesity, hypertension, and thrombotic diseases). This leads to increased costs of health care in those with poor literacy. Surprisingly, there is no data directly related to health literacy in interpreting laboratory test results.

Because of issues with health literacy, several groups have recommended that health information sites have content written at a 4th to 6th grade level. In a recent review of patient education materials provided by professional societies, none of the 16 societies had materials that were at less than a 9th grade reading level [5]. In a partial review of content from Lab Tests Online US, the average level of the articles was at the 10th to 14th grade level (unpublished data). To limit the impact of this high level of content, the opening sentences of each section in each article provide a summary of the material in a more simple fashion to provide content understandable at a 6th grade reading level.

3. Lab Tests Online users and their assessment of the site

Efforts to collect user data vary across the sites and have employed a variety of mechanisms. Site usage data provided through Google Analytics is available for all 17 sites in the network. Several sites also provide

users one or more forms through which they can provide feedback, including a "Send Us Your Comments" survey that is built into the left-hand navigation, a "Was this page helpful?" survey that appears on each page, a "Contact Us" form for submitting general questions and comments, and an "Ask Us" form that enables users to ask a laboratory scientist specific questions about their tests and test results. Finally, the Australian site has conducted focus groups and limited-time pop-up surveys to learn more about users and how they use the site. All of these internal assessments are unpublished.

Determination of who uses the Lab Tests Online sites has come from online surveys of users. In Australia in 2012 about half of the users were the planned target audience for the site i.e. patients or their caregivers. However almost one third of users were health professionals including doctors, nurses, allied health staff and pathology staff. The remainder were students and casual information seekers. Corresponding data from the US site in 2012 showed that two-thirds of users identified themselves as "patient, family member, or friend" while 21% indicated they were a "laboratorian or other medical professional" and 11% selected "other".

Data from Google Analytics gives a crude measure of user satisfaction through assessment of traffic to the site. This is most useful in detecting problems such as when a sharp drop in traffic to sites in several European countries was seen. Investigations revealed that this was due to these sites moving to a new Content Management System and a subsequent technical problem resulting in search engines being less efficient in finding many Lab Tests Online pages.

The majority (60%) of patients and caregivers in Australia use the site to seek information about a specific test or tests. Another 35% are looking for information about a specific illness and 14% do not have a diagnosis and are seeking information about their symptoms.

Australian users were asked to rate the site on their perceptions of the ease of navigation, ease of understanding the information presented, the tone of the website, quality of the information, and reliability of the information. Patients and caregivers and healthcare professionals rated the site around 8 out of 10 for all of these parameters.

Australian and US users differed in their opinions about the amount of information in the articles on the sites. As shown in Table 1.

The respondents in each country were selected in different ways. We will need to use standardized survey methods across the different sites to see if these between-country differences are real.

The aggregate response of all users to the same "Send Us Your Comments" survey shows increased user satisfaction with the level of information on the US site over time. Responding to almost half of all users who said they wanted more detail in the 2002 survey, the editors increased the level of detail as they updated content and added new material. The year-to-year survey results show a steady improvement in user satisfaction. In 2012, overall user satisfaction increased 8% over the 2002 survey, and those who felt that they wanted to see more detail fell 11%. The 2002 and 2012 survey results are shown in Table 2.

The most frequent specific complaint voiced by users in both the US and Australia was the lack of reference intervals on the site. This will be discussed further in the section on harmonization below.

4. Consumers lack information about pathology

The Australian management group have convened focus groups to assess attitudes to Lab Tests Online specifically and laboratory testing

Table 1
User assessment of amount of information on the US and Australian sites in 2012.

The level of information you found on this site was	Right amount of information	Not enough detail	Too technical
Australian users responding to a pop-up survey on the site	80%	18%	2%
US users responding to a standing request to "send us your comments"	59%	35%	6%

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