

LAB TESTS ONLINE-UK

ANNUAL REPORT 2016

Lab Tests Online-UK Mission Statement

'To improve the health of patients by increasing their understanding of laboratory tests'

Lab Tests Online-UK (<u>labtestsonline.org.uk</u> (LTO-UK)) is an online resource designed to provide patients and carers with easy-to-understand information about clinical laboratory tests.

It is peer reviewed: LTO-UK is written by practicing laboratory doctors and scientists with assistance from lay advisory specialists to help members of the public understand the many clinical laboratory tests that are used in the diagnosis, monitoring and treatment of disease.

It is non-commercial: LTO-UK does not search for nor receive commercial sponsorship. Support is generously provided by the Association for Clinical Biochemistry and Laboratory Medicine (ACB), the Royal College of Pathologists (RCPath) and the Institute of Biomedical Science (IBMS).

It is patient-centred: Its primary role is to help patients find understandable information on laboratory tests for particular diagnosis and/or conditions or diseases.

Management structure

The LTO-UK Board is accountable to the ACB through the Director of Communication and Publications.

Board members 2016

Chair: Dr Danielle B Freedman Treasurer: Dr William J Marshall Managing Editor: Dr Sally Stock Technical Lead: Stuart Jones Marketing and Promotion: Rebecca Powney Patient Liaison: Professor Jonathan Kay Patient Advocate: Dr Patricia Wilkie IBMS representative: Nick Kirk Royal College of Pathologists representative: Dr Tom Butler Administration: Dragana Landup-Horgan

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An editorial team and managing editor work under direction of the management board and are responsible for the website content. All editorial work is done on voluntary basis. Twenty one new editors have been recruited during 2016, which will enable content across all disciplines of laboratory medicine to be reviewed more frequently. The full list of contributors can be found on the website.

Principal Editors

Dr Brian Payne (news editor) Dr Tom Butler (haematology) Dr Charles Van Heyningen (biochemistry) Dr Matthew Buckland (immunology) Christopher Holmes (microbiology) Dr Tim Wreghitt (virology) Dr John Schofield (histopathology) Dr Nicole Corriette (GP representative) Dr Ian Godber (website comments advisor)

Historical context

The Lab Tests Online concept originated in the USA and was developed into a website by the American Association for Clinical Chemistry (AACC) and launched in 2001. The UK laboratory profession recognised the potential of this site at an early state and senior members of the ACB were successful in obtaining sufficient funding from the Health Foundation and the Department of Health (England) to develop a UK site. LTO-UK, with 1,800 pages, was launched by the Minister of Health, Rosie Winterton in June 2004.

The number of visitors to the site grew rapidly and LTO-UK is now part of an international collaboration of sixteen countries reaching patients throughout the world.

Communications and interest come from the public across the spectrum of health literacy with approximately 30% of visitors being healthcare professionals. While the site adopts a language and presentation style appropriate for easy public communication, where possible, the test and disease information provided reflects the different needs and expectations of all visitors.

The website

The LTO-UK team monitor site activity and identify the popular pages, search engines and links that carry visitors to the website. The content of the site continues to grow and evolve and is reviewed and updated at regular intervals. The independent and professional approach of LTO-UK (which has no commercial allegiance) is increasingly what separates it from other information sites and review of content by NHS professionals in the relevant laboratory speciality.

Following a turbulent number of years the visitor rate in 2016 has stabilised at around 260,000 visits per month (see Appendix A), higher than any previous year. Unlike last year, the visitor rate this year was not affected by any Google algorithm updates. Traffic from external websites with integrated links to LTO-UK doubled from around 25,000 to 50,000 visitors per month, thanks primarily to additional links within the NHS Choices website.

We have expanded the number of third party systems who maintain or are developing integrated links to LTO-UK and whilst this is currently responsible for a relatively small number of visitors to the site, we envisage this growing rapidly as the NHS England PatientOnline programme moves forward. The only major GP system that isn't currently working with us in this way is EMIS but we have developed some new contacts and hope to build on this relationship in 2017.

The LTO-UK app has been a major success with 18,624 downloads since its launch in June 2013. The number of active users has been relatively stable since we started monitoring at the beginning of 2016 at around 500/week (see Appendix B).

The @LabTestsUK twitter account grows steadily with currently over 850 followers. It provides the public with a direct route for engagement with our team and a social media platform for us to promote the website and actively engage with the public and key healthcare and laboratory peers.

2016 website statistics

| Total tests: 303 | Visits: 3,064,649 |
|------------------------|----------------------------|
| Total conditions: 114 | Unique visitors: 2,319,452 |
| New pages developed: 4 | Page views: 7,050,585 |
| Pages reviewed: 73 | |

App downloads: 5,191 (of which 830 were overseas)

The app is available for download in the UK only, however due to a change in the way Google Play lists the Android app these restrictions were bypassed and the app became available overseas. Although the restrictions have been reinstated it is not possible to guarantee that downloads from Google Play are limited to the UK. The iTunes account is limited to the UK.

International profile

In spring 2016, LTO was announced as a winner of the Digital Health Awards, an awards program that honours the world's best digital health resources. Hundreds of local, state and national health-related organisations and companies enter the competition. Well-known organisations like American Heart Association and CVS Health were also winners. Digital Health Awards is organised by the Health Information Resource Center[sm] (HIRC), a national clearinghouse for professionals who work in consumer health fields. Both the Digital Health Awards and the Health Information Resource Center are independent, and not affiliated with any organisation or company that enters the competition.

Lab Tests Online

LTO-UK editorial board has been successful in working with the AACC in promoting the adoption of Lab Tests Online in countries across the world – initially in Europe and now further afield in Australia, China, South Korea and Brazil. Currently, there are 16 international sites using 13 languages. Many non-UK sites initially based their material on that available on the UK site. The UK site continues to have a major editorial influence on Lab Tests Online worldwide.

Closer to home

In November 2016, LTO-UK was recommended in a report published on digital technology in the healthcare system by the Nuffield Trust. Entitled "<u>The Digital Patient: Transforming</u> <u>Primary Care?</u>", The report highlights the current state of digital technology and how new advances within the healthcare setting may help improve the patient experience and other outcomes. Patients have had access to their clinical records held by GPs since April 2016. Developing personalised health records held by patients, could allow seamless care across the whole health service. And it is here, where Lab Tests Online is featured in the report as an important educational resource to give patients the ability to know what their laboratory tests are and what the results mean.

The Department of Health's Information Strategy (2012) has set a ten year framework for transforming information provision that will enable patients and the public to have more control of the health and care information they need and access to it online. This strategy is further supported by evidence from Patient Online, which has already identified key benefits that directly relate to the work of LTO-UK including:

- **Expanded health knowledge for patients**: Better information can empower patients and carers, leading to increased health knowledge and health literacy. In turn, this can improve levels of patient satisfaction and wellbeing. Accessing online records means that patients can review up-to-date and relevant information pre- or post-consultation (including out of hours). This increases meaningful interaction and more shared decision-making between patients and their health professionals and encourages patient ownership of their own health and care.
- **Increased ability of patients to make more informed decisions**: Patients' satisfaction and wellbeing is increased by their ability to make more informed decisions about their health and care, facilitated by access to personal health records.

LTO-UK supports the Patient Online initiative and is engaging with users to improve the quality of their patient experience, by promoting the web site and app as essential patient resources to enable better understanding and control of their care and treatment.

The app has a review score of 4.5/5 on Android. The NHS app library is currently offline and iTunes don't currently provide a rating for it.

LTO-UK has taken opportunities in educating the public and healthcare leaders through the media, meetings and conference platforms

News articles published on the LTO-UK website during 2016 include the following:

http://labtestsonline.org.uk/news/familial-hypercholesterolaemia/, Child-Parent screening for risk of premature coronary heart disease , 19 December 2016

http://labtestsonline.org.uk/news/downs-update/, Update on antenatal tests for Down's syndrome, 7 November 2016

http://labtestsonline.org.uk/news/nipt-rhd/, A new DNA blood test for Rhesus-D negative women during pregnancy could spare treatment for thousands, 9 August 2016

http://labtestsonline.org.uk/news/daily-telegraph-article/, Daily Telegraph article directs readers to Lab Tests Online-UK, 7 July 2016

http://labtestsonline.org.uk/news/tb-test-for-drug-resistance/, Rapid molecular diagnostic test for drug-resistant tuberculosis may help save lives, 26 May 2016

http://labtestsonline.org.uk/news/screening-for-c-difficile/, Screening for carriers may reduce hospital-acquired cases of C difficile diarrhoea, 24 May 2016

http://labtestsonline.org.uk/news/nice-recommends-blood-tests-for-pre-eclampsia/, NICE recommends blood tests to help rule out suspected pre-eclampsia, 24 May 2016

http://labtestsonline.org.uk/news/lto-uk-champion-newsletter/, LTO-UK champion newsletter, 1 March 2016

http://labtestsonline.org.uk/news/screening/, Improvements recommended for NHS screening programmes that use laboratory tests for bowel cancer, cervical cancer and Down's syndrome, 1 February 2016

http://labtestsonline.org.uk/news/ovarian-cancer-screening-mortality/, Screening for ovarian cancer by monitoring cancer antigen 125 (CA-125) needs further assessment, 11 January 2016

Members of the LTO-UK board spoke and attended a number of events throughout the year including: '*ACB FOCUS*' in Warwick and '*The Annual Conference for the National Association of Patient Participation*' in Warrington. There has been overwhelming positive feedback from these events, increased networking opportunities and invaluable promotion of LTO-UK. The LTO-UK survey was published in the Annals of Clinical Biochemistry in November 2016.

The LTO-UK board monitor the progress of the website and the following three year (2014 - 2017) objectives have been met this year:

- to increase annual traffic by at least 10% year on year and to promote the use of the app to patients and health professionals
 In 2015 there were 2,394,050 visitors, in 2016 there were 3,064,649 visitors, representing an increase in the annual traffic of 28%
- to work with system suppliers to integrate links to Lab Tests Online within electronic patient record applications Currently the following systems have or are developing integrated links: *TPP*, *HealthFabric*, *iSOFT OMNI lab*, *SystmOne*, *INPS*, *Microtest*, *DrDoctor and i-Patient*

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• to increase links with other public facing websites, e.g. national health related charities and others. *NHS choices*, *ULCH OCS*, *and Welsh Specialist Virology Unit* currently have a links.

The future

LTO-UK objectives for the next three¹ years:

- to continue to implement the marketing plan²
- to increase annual traffic by at least 10% year on year and to promote the use of the app to patients and health professionals
- to ensure that GPs have direct links from their surgery to LTO-UK website
- to monitor and assess LTO-UK impact in primary care setting.
- to increase links with other public facing websites, e.g. national health related charities and others
- to secure permanent funding to support these activities
- to work with GP and patient record system suppliers to further integrate LTO-UK into patient facing applications.

¹Business plan 2014–2017

²Marketing plan 2013–2015 produced by Katy Heaney in July 2013.

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Financial details

LTO-UK does not search for nor receive commercial sponsorship. This is considered to be important to assure all users of our independence.

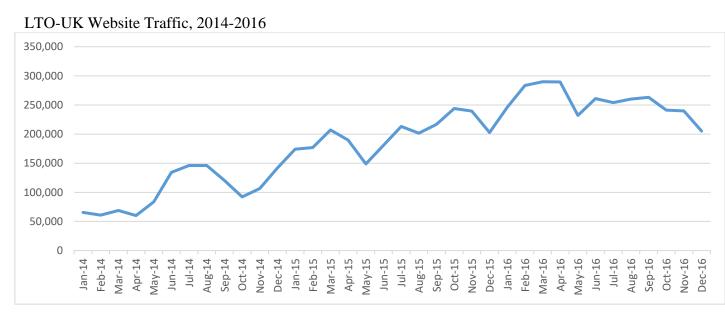
LTO-UK is administered through the Association for Clinical Biochemistry and Laboratory Medicine and does not publish separate accounts. These are included within the Association's audited accounts. It had a nominal balance at the beginning of the year of £44,921. Total expenditure (excluding VAT) was £25,920. The major items of expenditure are the salary of the part-time administrator and the licence fee payable to the American Association for Clinical Chemistry. Total income was £30,000. The ACB contributes to the project both financially and through the provision of additional administrative support as required, and by providing accommodation for meetings, to a total of £10,000; grants of £10,000 each were made by the Institute of Biomedical Science and the Royal College of Pathologists. The closing balance (31 December 2016) was £49,001. We are having discussions with patient groups and other professional organisations with a view to securing long term funding. These figures are provisional end of year figures, pending audit.

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Appendices

Appendix A



Appendix B

