**Lab Tests Online 2017-19 – Website extension**

# Final Performance Report – July 2019

## Executive Summary

The key objectives of Lab Tests Online Australasia (LTOAU) for funding period July 2017 to June 2019 have been achieved.

LTOAU content for all genetic tests listed in the Medical Benefits Schedule have either been updated or created for the newly introduced tests.

The first phase of the new initiative of “Explaining your pathology report” has been completed. 51 pathology tests have new content with information to assist in interpreting test results. These have been produced using text and more recently animation and videos. The effectiveness of the content has been tested with universally positive responses from consumer reviews.

The subject areas for other new content pages have included the harmonisation of test intervals and test names, in line with updates to PITUS recommendations, for 30 biochemistry tests.

Particular effort has been made to improve ease of access to information on LTOAU site with a redesign of the front page. Videos, animation and graphic illustrations are being gradually introduced for all content areas to increase appeal to a broader range of levels of literacy.

Record numbers of visitors continue to reach the LTOAU site. The chart below shows the period from July 16 to June 19. The yearly total numbers are shown as a red bar while the monthly visitor numbers are shown as blue bars. From July 17 to June 18 there was a 47% increase in visitors while from July 18 to June 19 there was a 40% increase. In total there has been more than 2.2 million sessions  for the last 12 months.

Below is a Table indicating achievements against the target performance indicators.

| **No** | **Performance Indicator** | **Target** | **Achievement** |
| --- | --- | --- | --- |
| 1 | No. of tests identified & updated to include alternative media e.g. video/animation | 5 | 9 videos explaining 33 tests2 animations explaining 4 tests(37 tests in total) |
| 2 | No. of commonly requested tests customised to include the “Explaining your pathology report” format module to LTOAU | 50 | 51 |
| 3 | Demonstrated increase in users/visitors accessing the website (provided in both raw data and as a percentage increase in website traffic) | Increase in numbers over activity period | No. of visitors in 16-17 – 1,068,325No. of visitors in 17-18 – 1,068,325(47% increase)No. of visitors in 18-19 – 2,195,548(40% increase) |
| 4 | No. of new content of identified genetic tests uploaded to LTOAU | 5 | 11 |
| 5 | New content increasing the understanding of tests explaining your pathology report. | Provision of examples that demonstrate an enhanced/increased level of comprehension among users accessing the website. | We have provided 9 videos, 2 animations and 3 text-based explanations of test results as new content applied to a total of 51 tests.  |

A new phase of LTOAU development, as part of extending its reach has been to strategically consult with and formalise the relationships with key stakeholders. Priority organisations are the Australian Health Consumer Forum, Australian Digital Health Agency, pathology providers, front line clinicians, RCPA and RACGP. The ideal is for more active participation of health consumers within LTOAU management and as reviewers of all LTOAU content. This model will benefit from input from the stakeholder groups so that where ever possible the use of LTOAU is embedded digitally into workflows within the clinical and pathology information systems.

An industry partnership has been established with the Australian Technology Network. Curtin University will be the first pilot site. This project will engage the School of Business marketing expertise, School of Computing, Mathematics and Data Scientist digital skills and data analytics and School of Humanities to design the LTOAU visual library and assist with graphic design and video making. Ongoing collaboration with these and second tier stakeholders will be essential to raising awareness in diverse clinical settings and with disease support groups.

## Detailed review of all activities stipulated in funding agreement and achievements 2017-19

### **Review and extend the content of the recently developed Genetics Module**

**Planned Activity**

1. Review all new genetic tests added to the MBS.
2. Review all relevant tests related to inborn errors of metabolism (IBEM). Where necessary prepare relevant LTOAU content.

**Achievements July 2017 – June 2019:**

1. We performed a gap analysis on genetic tests available on the MBS and not on the website. Eleven tests were identified and then suitable authors to write the articles were selected. These writing tasks, their review by our Chief Medical Editor and placement in the website were all completed within the two-year funding period.

Nine of the items are as new tests and two are shown as new content being added to existing information. Table 1 shows the complete list of genetic tests added in the funding period.

There were no major complications with this part of the project other than the ongoing problem of finding volunteers to agree to write material and then obtaining it within deadlines. There is no shortage of expertise but the time to do voluntary tasks such as LTOAU editing becomes less and less for all our professional colleagues. This problem affects all of our editing and reviewing activities and will be dealt with in more detail towards the end of this report.

**Table 1: MBS Genetic Tests and status of new content preparation**

| **MBS Genetic Tests** | **Gap Analysis** | **Status** |
| --- | --- | --- |
| Analysis of the PMP22 gene | >200 tests performed 2018 | Content created and uploaded as new test listing |
| Determination of HLAB5701 status by molecular techniques | Testing for hypersensitivity to anti- HIV drug. 600+ tests in 2018 | Content created and uploaded as new test listing |
| Characterisation of the gene rearrangement FIP1L1-PDGFRA | Existing information listing in LTOUS and Sonic website | Content created and uploaded as new test listing |
| Test of melanoma tumour tissue relating to BRAF V600 mutation status | Companion test for dabrafenib/ vemurafenib done by RPAH, Sydney. | Content created and uploaded as new test listing |
| Detection of germline mutations in the RET gene | Fewer than 100 tests in 2018, mostly in NSW | Content to update existing listing created and uploaded |
| Characterisation of mutations in the MPL mutation (gene) | Test rarely done in isolation | Content created and uploaded as new test listing |
| Detection of mutation of the FMRI gene by Southern Blot  | Covered by existing FMR1 pages | Content created and uploaded as new test listing |
| Detection of germline mutations in VHL gene | Good information on Cancer Council website.   | Content created and uploaded as new test listing |
| Detection of somatic mutations in von Hippel-Lindau (VHL) gene | Very rarely performed | Content created and uploaded as new test listing |
| 17p chromosomal deletion | Used in relapsed CLL.8 services since item amended | Content created and added to “Tests” section in listing of Leukaemia condition |
| Test of colorectal cancer tumour tissue relating to RAS gene mutation status | Similar to VHL above | New test completed and on website |

1. Inborn errors of metabolism (IBEM).

A gap analysis showed that there was no additional material to be added to the site for IBEM.

### **Apply the new “Explaining your pathology report” module to a wide range of tests on the website**

**Planned Activity**

*Using a previously described facsimile of a laboratory results form with explanatory information overlaid, customise to individual tests selected based on consumer group feedback and b. tests with highest numbers of LTOAU visits;*

*Ensure a minimum of 50 requested tests are updated with the “Explaining your pathology report” module within the Activity Period.*

**Challenges associated with this activity**.

When the target of 50 tests was set for updating the test content along the lines of our previously established “Explaining your pathology report” section, it was assumed to be a relatively easy task. This proved not to be the case and this activity was the only part of this Funding Agreement that was associated with significant challenges.

The first such challenge is to provide a general explanation about results and avoid what might appear to be individual interpretation which we take every step to avoid for obvious reasons. We did seek suggestions from some of our regular pathologist and scientist reviewers as to how to best provide more explanation and while they acknowledged the difficulty of the problem, they did not provide any tangible solutions.

Having agreed on a possible template to use for results explanation that we could apply across multiple tests, implementation of the template proved difficult for our website provider and we started to incur significant costs. This problem was eventually resolved to some degree and as we explain below, we have used this format for explanation of some tests.

As part of attempting to resolve these issues we considered taking a different approach and using other media such as video to explain what tests are and what the results might mean. And following that initiative we discovered a very inexpensive animation software which we have also uses to explain results and laboratory processes.

Thus out of the challenges described above have come a range of solutions all of which we believe have proved effective.

**Achievements July 2017 – June 2019:**

This activity incorporates aspects of Activity 3 (see next item) which focuses on improved readability, literacy and accessibility.

We have used 4 different media formats to provide some further explanation of 51 tests thus just exceeding our target. Table 2 below summarises the numbers of test groups and total numbers of tests which Table 3 shows the details of which tests have been covered by which media format.

**Table 2. Summary of media formats for explanation of test results and number of tests.**

| Media format | No of test groups (No of tests) |
| --- | --- |
| Text explanation of a set of results | 3 (14) |
| Video of expert providing explanation | 6 (12) |
| Video of expert talking to a set of results | 3 (21) |
| Animation | 2 (4) |

**Table 3: Explaining Your Pathology Report Items**

| **No** | **Test/Panel** | **Content Format** | **Narrator** | **Project Status** |
| --- | --- | --- | --- | --- |
|  | HPV | Video | Peta Fairweather | Created and uploaded |
| 1 | HPV |  |  |  |
| 2 | Pap smear |  |  |  |
| 3 | HbA1C | Video | David Sullivan | Created and uploaded |
|  | Complete blood count | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 4 | Haemoglobin | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 5 | Haematocrit | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 6 | Red cell count | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 7 | Mean cell volume | Video and voice over results | Teresa Marzulli | Created and uploaded |
|  | White cell count | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 8 | Neutrophils | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 9 | Lymphocytes | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 10 | Monocytes | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 11 | Eosinophils | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 12 | Basophils | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 13 | Platelets | Video and voice over results | Teresa Marzulli | Created and uploaded |
| 14 | Influenza virus | Video | Jenny Robson | Created and uploaded |
|  | Liver Function Tests | Video and voice over results | Greg Ward | Created and uploaded |
| 15 | ALT | Video and voice over results | Greg Ward | Created and uploaded |
| 16 | AST | Video and voice over results | Greg Ward | Created and uploaded |
| 17 | Alk. Phos. | Video and voice over results | Greg Ward | Created and uploaded |
| 18 | GGT | Video and voice over results | Greg Ward | Created and uploaded |
| 19 | Total Protein | Video and voice over results | Greg Ward | Created and uploaded |
| 10 | Albumin | Video and voice over results | Greg Ward | Created and uploaded |
| 21 | Bilirubin | Video and voice over results | Greg Ward | Created and uploaded |
|  | Thyroid Function Tests | Animation and results form | Kevin Carpenter | Created and uploaded |
| 22 | TSH | Animation and results form | Kevin Carpenter | Created and uploaded |
| 23 | FT4 | Animation and results form | Kevin Carpenter | Created and uploaded |
| 24 | FT3 | Animation and results form | Kevin Carpenter | Created and uploaded |
| 25 | Troponin | Video | Louise Cullen | Created and uploaded |
|  | Electrolytes and urea | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 26 | Sodium | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 27 | Chloride | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 28 | Potassium | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 29 | Bicarbonate | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 30 | Urea | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 31 | Creatinine | Text explanation of a case | Bruce Campbell | Created and uploaded |
|  | Iron studies | Video and voice over results form | Bruce Campbell | Created and uploaded |
| 32 | Iron | Video and voice over results form | Bruce Campbell | Created and uploaded |
| 33 | Transferrin | Video and voice over results form | Bruce Campbell | Created and uploaded |
| 34 | Transferrin Saturation | Video and voice over results form | Bruce Campbell | Created and uploaded |
| 35 | Ferritin | Video and voice over results form | Bruce Campbell | Created and uploaded |
|  | Protein electrophoresis | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 36 | Electrophoresis | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 37 | Immunofixation | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 38 | Beta 2 Microglobulin | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 39 | Urine free light chains | Text explanation of a case | Bruce Campbell | Created and uploaded |
|  | Lipid studies | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 40 | Cholesterol | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 41 | Triglycerides | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 42 | HDL | Text explanation of a case | Bruce Campbell | Created and uploaded |
| 43 | LDL | Text explanation of a case | Bruce Campbell | Created and uploaded |
|  | Faecal calprotectin | Video | Daman Langguth | Created and uploaded |
| 44 | Faecal calprotectin | Video | Daman Langguth | Created and uploaded |
|  | Autoantibodies | Video | Daman Langguth | Created and uploaded |
| 45 | Antinuclear antibody | Video | Daman Langguth | Created and uploaded |
| 46 | Thyroid antibodies | Video | Daman Langguth | Created and uploaded |
| 47 | Coeliac antibodies | Video | Daman Langguth | Created and uploaded |
| 48 | Neutrophil antibodies | Video | Daman Langguth | Created and uploaded |
| 49 | Platelet antibodies | Video | Daman Langguth | Created and uploaded |
| 50 | Red cell antibodies | Video | Daman Langguth | Created and uploaded |
| 51 | CRP | Animation | Kevin Carpenter | Created and awaiting uploading  |

All LTOAU  videos are hosted on the LTOAU  YouTube website. The videos attract significant traffic with the Liver Function Test Results video being viewed by more than 1000 people per week. Other particularly popular videos are Full Blood Count, Human Papilloma Virus tests and Troponin Testing to identify myocardial infarction.

More detailed evaluation of effectiveness of the Talking Results: Liver Function Tests video was conducted using a consumer survey embedded on the LTOAU  website. The responses were universally positive.

In total, there are 23 videos and animations on the website and on our YouTube Channel, providing ways other than the written word for consumers to access information on tests and related topics.

### **Improve the readability & accessibility for consumers of existing content.**

**Planned activity**

*Engage a medical writer to aid the editorial process to review and change text and add new drawings and other graphical material to improve consumer’s understanding of scientific content.*

*Review to identify content for improvement and update tests selected for alternative media such as video/animation and include on LTOAU Website.*

*Undertake ongoing review of key tests to improve readability through modified text and addition of graphics.*

*Actively target and promote the website to consumers, medical students, and requesters/referrers (e.g. GPs) including seeking feedback for improvement.*

**Achievements July 2017 – June 2019:**

* Video production

The use of videos to provide an alternative to test-based information represents one of the major achievements of this funding period. That we have been able to do so many is due in part to the generosity of Sonic Pathology who have made the time available for one of their employees, Billie McCrane, to produce the video material for LTOAU.

Following the placement of the LFT video on website we conducted a consumer survey via a popup request for feedback from visitors to the LTOAU website.

More than 300 consumers responded to the survey; the responses from both consumers/patients and healthcare professionals were overwhelmingly positive and it clearly helped many people understand LFT results.

The pitch, language and amount of scientific information delivered appear to be at a level that reaches the majority of our audience. We recognise that some people will require more information (but they can find this elsewhere on the website), while others may not grasp everything being said (although they have the option of replaying the video if this helps them).

Given these responses, we were encouraged to continue using this media format as a way to communicate more information about test result and other aspects of LTOAU.

The full report on this consumer feedback in shown as Addendum 1 at the end of this report.

* Application of harmonised reference intervals

Another aspect of providing explanation about test results and of simplifying the information we provide relates to reference intervals. In this funding period harmonised reference intervals for approximately 30 analytes became widely available in laboratories and accordingly we added this information to the relevant tests.

In support, we produced a short animation feature which explains the basic concepts behind reference intervals, how it relates to the concept of normal and what such harmonised intervals mean for those tests where they apply.

This initiative directly addresses the lack of understanding amongst consumers as demonstrated in the consumer survey.

* Application of standardised test names

Another source of confusion for consumers is the variation in test names that occur across the pathology service. A project called Pathology Information, Terminology and Units Standardisation (PITUS) exists with the goal of ensuring an individual test has the same name no matter where it is measured.

Although this was not in our project plan, we believed that we should support this initiative and accordingly we have standardised all the chemistry tests on LTOAU to the recommended PITUS name. This initiative has met with some criticism as a result of the fact that since most laboratories are still yet to standardise their test names, the introduction of PITUS names on LTOAU may cause further confusion for consumers. We have thus refrained from standardising the tests in disciplines other than biochemistry.

* Rewriting of test information

We believe a challenge for LTOAU is to make our information accessible to as wider group of consumers as possible including those with lower than average levels of health literacy. Much of pathology is complex scientific information and therein lies the challenge of communicating it in a form that can be understood. Anecdotal feedback suggests that there is considerable room for improvement and a more concerted effort in this area including the engagement of greater consumer input will be the priority of our new Chair, Sue Benson.

During this funding agreement we have undertaken a major rewrite of the *Understanding your tests* section of the website which has been overseen by our medical writer, Pamela Robson following extensive review by several of our scientific reviewers. We believed this area was a priority since it describes the procedures through which consumers directly interact with the pathology system.

* Redesign of LTOAU front page to highlight content more effectively and streamline searches

The other primary activity to improve the LTOAU readability and access has been a major re-design of the front page where most visitors arrive when using LTOAU. The project was prompted by consumer feedback that ease of access and navigation through the site was excessively complex.

The major changes to the front page proceeded after consultation between current LTOAU management groups and the hosting company (Heartburst). The front page now highlights the most common tests with streamlined steps to content. The final product was completed and released in late June and is viewable at the LTOAU URL ([www.labtestsonline.org.au](https://www.labtestsonline.org.au/)). This initiative represents a significant improvement. However, there are plans for further enhancements and overall optimisation of the website as one of the LTOAU strategic priorities over the next 6 - 12 months.

### **Extend the reach of LTOAU through partnerships with other organisations.**

**Planned activity**

*Look to develop collaborative relationships with external organisations to help extend the reach of LTOAU including National Prescribing Service (NPS), the My Health Record team and the Australian Medical Students Association (AMSA).*

*Supply additional content for use on the NPS website.*

*Continue to engage a Search Engine Optimiser (SEO) organisation to ensure that access to LTOAU by consumers is optimized.*

**Achievements July 2017 – June 2019:**

1. **Collaborative relationships**
* Australian Digital Health Agency: My Health Record

We have maintained ongoing contact during this funding period with the Australian Digital Health Agency (ADHA) primarily through Paul Carroll (Program Manager Diagnostics Solutions).

A link to the LTOAU has been placed in the pathology section of My Health Record.

LTOAU has been encouraging pathology providers to include the LTOAU URL and where possible the hyperlink to the site on printed and digital pathology reports. Northern Territory Pathology were the first to do this in June 2019. Queensland Health Pathology are in the process of implementation and there is agreement in principle to from other public and private pathology providers, including Sonic.

The next phase of collaboration with ADHA is currently being developed and will be discussed at the time of meeting in late July 2019.

* Australian Technology Network: University Industry Partnership

LTOAU has established a partnership with Curtin University as part of the and will commence in August 2019. It will encompass the Curtin Schools of Business and Marketing, Data Science and Design. This collaboration will be an ongoing relationship with university students and academic supervisors provided consultation services to improve the LTOAU website user experience, search engine optimisation, graphic and video content and operationalise the Google Analytic website traffic.

The input into LTOAU function is expected to lead to significant enhancements as well as build capacity in the sector for more effective consumer health information resources. The Google Analytics analysis will enable more detailed evaluation of LTOAU  site use, consumer information requirements in subject area of diagnostic test and monitor changes overtime particularly with the uptake of direct consumer access to pathology results.

* Pathology Awareness Australia

Interaction between ourselves and PAA continues including a presentation from the Chair of PAA, John Crothers to the Board of LTOAU in December 2018. Ongoing discussion proceeds on how best we can mutually support each organisation.

* PathWest

An opportunity arose at short notice in January 2019 to collaborate with PathWest, the public provider of pathology in Western Australia, in an application for Federal grant money. The application is for funds to enable links to be placed both within patient results uploaded to My Health Record and in other information systems used by health carers, that will enable both these groups to access directly, specific test or other information within LTOAU.

The grant will fund the required IT changes and development within various information systems within PathWest as well as changes to LTO content. At the time of this report we are yet to hear whether our application have been successful.

1. **Search engine optimisation (SEO), social media and Google Analytics**.
* With the appointment of Rajeev Chandra to the LTOAU management group we now have the expertise to manage our SEO activities in house as well as a better understanding of how we can use Social Media and other communication channels to promote the organisation. Our social media strategy aims to drive users to LTOAU via Facebook, LinkedIn, YouTube and Twitter and we see the potential to develop this strategy further in order to attract younger consumers.
* We also continue to use Google Ads to drive traffic to the site. This strategy is becoming increasingly unsatisfactory due to their frequent rejection of our content because of the inclusion of words that fall foul of their filters such as the names of drugs.
* We have become more aware of the importance of the data generated by Google Analytics and what it tells us about the composition and interests of our visitors and, as indicated above, this data will be more extensively analysed as part of the research project with Curtin University.
1. **Internal promotion**

We believe it is important to keep the profession aware of LTOAU and its activities for two major reasons:

* To encourage members of the profession to volunteer their services as content editors/reviewers
* To act as a communication channel between consumers and quality related activities in pathology.

There are two activities of note in this area during this funding agreement:

1. LTOAU  Poster Presentation at RCPA Pathology Update Meeting Mar 2019

A poster titled *Lab Tests Online Australasia: A Key Partner in Increasing Pathology Health Literacy* was presented at the RCPA Annual Pathology Update meeting (see Appendix 1). The analysis included in the poster highlighted the value of the LTO as measured by site visits. The site visit activity was broken down by pathology discipline and topics. The project was an opportunity to raise awareness within the pathology profession of the importance of LTOAU   and highlight the value presented by the contributions of content writers.

1. LTOAU  Invited Speaker RCPA QAP National Quality Workshop Sydney March 2019

LTOAU was invited to present on the topic of how it supports efforts to improve the quality of pathology testing at the annual national meeting of quality managers from pathology practices in Australia and New Zealand. The presentation titled *Lab Tests OnlineAU: A Tool for Improving the Quality of Pathology Testing* was well received and generated discussion about how consumers could be more active in quality improvement priorities.

1. **Strategic planning and governance of LTOAU**

There is a need for a new 3-year strategic plan for LTOAU and this includes defining a new governance structure or board. Accordingly, discussions have commenced with a wide range of organisations including those mentioned above under collaborative partnerships and those such as the Royal Australasian College of Pathologists, the Pathology Information and Terminology Units, Royal Australasian College of General Practitioners, Australasian Association of Chemical Biochemists, the Health Consumer Forum, and key public pathology practices. It is anticipated that these discussions will be followed up with meetings in the period of July-September 2019.

Part of the strategic planning process will involve how to make LTOAU a more sustainable organisation in the future and this issue is dealt with in more detail below.

The themes identified as the future strategic priorities of LTOAU are:

1. Modification of LTOAU management, content generation and review processes to enable increased health consumer leadership and participation in the organisation.
2. Optimise LTOAU functionality for ease of use, wider range of literacy levels and capacity for direct interface with pathology test requesting and resulting processes and My Health Record.
3. Integration of LTOAU into the Australian digital health strategy
4. Formalised partnerships with RCPA, pathology practices, health consumer organisations, primary care, ADHA, medical software companies, universities and other health worker training organisations.
5. Develop research stream around pathology health literacy and improved measures of effectiveness of LTOAU
6. Establish the appropriate governance systems and funding sustainability for the long-term future of LTOAU

###  **Promote LTOAu to consumers**

**Planned activity**

*Complete the development of the LTOAU app and ensure the app is made freely available to and consumers.*

*Actively promote the LTOAU app through AMSA and to consumers through the website.*

**Achievements July 2017 – June 2019:**

The LTOAU smart device app was upgraded and released for use in June 2019.

Shortly after the start of this funding agreement it was decided that the app and promotion in general should focus on consumers and efforts to liaise with the Australian Medical Student Association (AMSA) should discontinue.

A new LTOAU information summary sheet with current usage data and infographics has been produced to be used for stakeholder engagement with ongoing benefits of increasing awareness and referrals to the LTO website (Addendum 3).

Promotion of LTOAU in general continues through all the efforts described above and the numbers of visitors continues to grow (see previous stats in the summary above).

**Sustainability of LTOAU**

There have been a number of developments associated with LTOAU in the 24 months of this funding period that are separate to the activities listed in the agreement but are significant and we believe relate to the issue of the sustainability of the organisation into the future. Sustainability is important because we anticipate that far more healthcare consumers will be visiting LTOAU in the future as a result of the development of My Health Record and this will place new demands upon the organisation.

**Personnel and succession planning**

During the time of this funding agreement there have been significant changes in the personnel associated with LTOAU and we they represent managed succession planning which is important for the sustainability of the organisation.

Chair of LTOAU

A new Chair of the LTOAU Board was appointed during the second year of this funding period. Dr Susan Benson is a Microbiologist/Infectious Disease physician from Western Australia and succeeds Tony Prior who was an interim appointment after the resignation of Dr Louise Wienholt. Amongst the many benefits of Sue’s appointment include that fact that her parent discipline is Microbiology and therefore brings different professional expertise to a Board that has to some extent been dominated by biochemists. Furthermore, Sue has a range of interests that will be of direct relevance to LTOAU including research, the quality of pathology and how it impacts consumers. Our ability to reach out and collaborate with new and relevant organisations (as detailed in section 4.1 above) has been considerably enhanced since Sue’s appointment.

Social media and website manager

We have become aware that there are multiple ways that consumers can arrive at a website such as LTOAU and we now need to use these other channels for promotion purposes. While these are often grouped under the heading of social media, they include other tools or communication channels such as LinkedIn, You Tube and Google Ads. Accordingly, we now have the expertise to manage this with Rajeev Chandra who was appointed at the beginning of this funding period. In addition Raj also manages the overall operation of the website and liaises with our website provider Heartburst.

Content placement officer

Another key task associated with LTOAU is the placement of content, both new and existing material that has been edited as part of our regular 3-year review process. This process does require someone with laboratory experience and we appointed Julie Sherfan 18 months ago to take on this task. Julie is a younger scientist at Royal Prince Alfred hospital who has commenced her RCPA Faculty training and as well as having her professional knowledge and skills, Julie brings a knowledge and understanding of website structures and software which has already been of considerable benefit.

Sustainability and content review process

At any one time there are approximately 20-25 scientists, pathology specialists and pathology trainees who are engaged in writing new material or more commonly reviewing existing content to check for its accuracy and currency. A few of our Editor/Reviewers have been with us since we started 12 years ago but there is what can be described as an ongoing churn in such critical people and one of the tasks of the LTOAU manager is to be constantly seeking out new editors from the profession who are willing to volunteer their time.

Needless to say, as laboratories become ever busier, this task is becoming more difficult and time consuming although we stress it does remain manageable. However again in the interests of sustainability it is important that we try to plan for a situation where we have more willing editors that we need at any one time because we anticipate that with more visitors we may need to consider reviewing our material more often than every 3 years. This will require more editors and, importantly, they will need to have improved skills of communicating with the lay public.

Sue Benson is leading initiatives to address this situation including the possibility of formally making the task of reviewing material for LTOAU an integral part of the training of scientists and pathologists.

Value for money and funding

It is probably more appropriate for others external to LTOAU to judge whether as an organisation we represent value for money. Furthermore, we have no data from similar organisations with which to compare activities and costs. However, we venture to suggest, that a website which provides up to date and scientifically accurate information at a total cost of less than $200,000 per year and attracts in excess of 2 million people, is reasonable value for money. We would welcome the opportunity to have our output and costs compared to other similar organisations.

Leaving aside the issue of the amount of money, perhaps a bigger issue is the nature of our episodic funding. This is not a new issue and to some degree we have become used to the expectation that we must apply for new funding every 1-2 years and which must be devoted to new initiatives. However, as we write this report, we have no funding and the services of the website will have to be continued through voluntary efforts. AACB will continue to pay for what might be called the infrastructure of the website but the work that is required to maintain the currency of its content will require those of us who form the management group to provide their time voluntarily. This, needless to say, is not a sustainable arrangement at a time when, as indicated previously, more and more people are likely to be visiting LTOAU. An urgent matter for the new Board of the organisation are renewed efforts to obtain what we would call sustainable funding.

Addendum 1: Consumer survey of responses to LFT video

Addendum 2: LTOAU RCPA Pathology Update 2019 Poster

Addendum 3: LTOAU Infographic Summary June 2019

***Dr Andrew St John***

***On behalf of the LTO Management Group***

***Australasian Association of Clinical Biochemists***

***23rd July 2019***

Addendum 1

**Survey to Assess Consumer Response to LFT Results Video**

**Report Prepared by Lab Tests OnlineAU**

**1. Overview**

From the end of 2018 and throughout the first months of 2019, the majority of Australians can expect to be given direct access to their pathology test results through My Health Record (MHR). As pathology laboratories around Australia upload results into the system, consumers will be able to see first-hand, documents previously only received by their doctors. For many people, this will be the first time they have encountered a pathology results report.

Results forms can be confusing and conversations around health can be stressful, impacting on a person’s ability to recall information provided during a medical consultation. Globally, there is an acceptance that consumers need support not only to help them understand the tests that are being carried out on their behalf, but to help relieve unnecessary anxiety. **Lab Tests OnlineAU is being used by MHR to help address this. A direct link is being embedded in each consumer’s pathology results report page that takes them directly to the Lab Tests OnlineAU home page.**

**In preparation for this, Lab Tests OnlineAU is exploring ways of providing supportive information that is of practical use to consumers. Mindful that we must be able to reach a broad range of literacy levels, our first project is a proposed** series of short videos. Called *Talking Results,* each of these videos will look at a test that is commonly requested by doctors. It will explain what is being tested and what the results can show. We cannot interpret the meaning of someone’s personal results; instead, the aim is to provide information that can help them ask the right questions of their doctors or recall what they’ve already been told.

We recognise that the information we give cannot be too detailed, both for reasons of consumer comprehension and the complexity of testing in the clinical settings. In order to make sure we are providing information that is both informative and understandable and presented in ways that people find helpful, we have produced a trial video and conducted an online survey with our **Lab Tests OnlineAU** users to gauge their responses. Attached to the survey was a call-out for comments and suggestions from health professionals, who are uniquely placed to provide insights into the patient experience.

**2. The Trial Video – Liver Function Tests Results**

Our first video has been designed to support people who have received their results for Liver Function Tests. This is one of the most common tests ordered and is a combination of tests performed on the same blood sample and reported together. The video focuses on a generic Liver Function Test results form with a voiceover explaining what each of the component tests are measuring and why. The form is animated with the results highlighted and ‘popping out’ when mentioned in the script. Relevant background footage is used to make the video more visually interesting and to give the viewer some ‘landmarks’ to help in recalling information. As well as providing information on the tests, the video briefly explains reference intervals and emphasises that results falling outside these parameters are not necessarily something to be alarmed about. Also, it urges the viewer to discuss results with their doctor. Language is plain and straightforward, medical terms and jargon have been avoided, and the video is captioned so that it can be used without sound.

**3. Research Method**

The research was conducted through an online pop-up survey on the **Lab Tests OnlineAU** website. Participants were asked to watch the video and then answer questions. Comments and suggestions were sought from health professionals. In this way, we were able to gather both quantitative and qualitative information.

**4. Lab Tests OnlineAU User Demographics**

**Since its beginning in 2007, the demographic of Lab Tests OnlineAU has been skewed female (65%) and younger. Broadly, there has been a split of about 70:30 between patients /carers and health professionals. Traffic to the website has been growing year by year. On an annualised basis, as of September 2018, there were 1.7 million yearly visitors.**

**LAB TESTS ONLINEAU VISITORS BY GENDER**

**5. Research Findings**

**(Part A) Consumer Survey**

The online survey was primarily for consumers with a further comment section included for health professionals. The survey recorded 318 people as starting the questionnaire but not all participants answered all questions. During the survey period (three weeks) an estimated 1,100 people watched the video. It’s possible that many people watched the video but did not participate in the survey.

There were many more consumers who took part compared to health professionals. Of the 318 participants 75.16% were consumers and 24.84% were health professionals.

**Q1. Were you worried about your LFT results?**

Slightly more than half of participants described themselves as not worried (51.64%). However, almost half (48.36%) expressed themselves as worried.

**Q2. Did you find the video helpful in understanding what was being tested?**

The large majority of people (80%) found the video either extremely or very helpful.

**Q3. Was there anything in the video that stood out as being particularly helpful?**

About 60% of people thought the video was ‘generally helpful’.

Of those who provided comments, the majority cited the way the video explained each of the liver enzymes being measured in the LFT and the reasons why they were being measured:

* ***“What each chemical was and what it did e.g. albumen and highlighting (in red) bits of the results sheet so we know what to look at as it’s being explained.”***
* ***“I liked having an explanation for each individual enzyme.”***
* ***“I focused initially on ALT (which in my case is high) but it was good to learn about other things.”***
* ***“ALP &GGT results to differentiate between bone & liver disease.”***
* ***“The ratios of high offer diagnostic relevance for discerning between liver and bone conditions.”***
* ***“Explanation of abbreviations.”***

Some respondents liked the fact they were reassured that highs and lows were not necessarily something to be alarmed about.

* ***“That elevated levels do not necessarily mean there is something wrong.”***

Some respondents liked the whole video.

* ***“Everything!”***
* ***Straightforward explanation put the test into context.***
* ***“It was good to know more about the results - like what AST, alb, CGT were measuring.”***
* ***“The explanation of every item gives good insight to the results and can only benefit us in the long run, helping us to look after our liver.”***

**Q4. Was there any part of the video that you found confusing or not helpful?**

The large majority of people – 90% – did not find the video confusing. Of the few people who made comments, many comments were quite specific to their personal situation.

* ***“My pathology report says high ALP is when it is over 115U/L, normal range 30 to 115. The video indicated normal range is up to 150. If the normal range is adjusted for age/gender perhaps that should be mentioned.”***
* ***“Suggested higher bilirubin results are bad. Ignored benign bilirubin situations. There should be more nuance”***
* ***“At 1:15 the video refers to acute hepatitis - many people think 'acute' refers to the severity of a disease rather than one with a recent onset.”***

Three comments were more broadly based.

* ***“All the acronyms and official names - just stick with the acronyms maybe?”***
* ***“It went a little too quickly - I'd have preferred it slowed so I could better absorb the detail.”***
* ***“All of it.”***

**Q5. Was there any information missing from the video that you think should be included (bearing in mind that we cannot interpret results)?**

About 90% of people did not think any more information could be included. Of those few who commented, some referred to having more information on normal levels.

* ***“Clearly defined range of levels.”***
* ***“How far above the ‘upper limits of normal’ is considered cause for concern.”***
* ***“I agree with your choice to not show ranges of normal test. This is rightly for the GP to interpret with the patient, you may or may not state that biopsy results are not a part of LFT.”***
* ***“Perhaps mention that what is ‘normal’ must consider age/gender.”***

Some people wanted more information on the relationship between test results and other conditions, presumably reflecting their own situation.

* ***“Perhaps relationships to liver function and other diseases such as celiac.”***
* ***“What non-common (hepatitis, fatty liver disease) conditions are relevant to liver function tests.”***
* ***“Elevated GGT in a non-drinker.”***
* ***“I was pregnant and did the liver function test. Some of my results were high and the Dr and I were extremely worried. She checked previous results and said that something was wrong. She asked if I had eaten breakfast before doing the test. I did. We redid the tests again and everything was NORMAL. You should fast before doing the test and people need to know this!”***

One person was confused by the fact we were using a generic results form (as labs differ in the way they present information.) We explained this, but perhaps we did not spend enough time on this.

* ***“My test record is different to that shown.”***

**Q6. Did you look at other pages on the Lab Tests OnlineAU website that give more detail about Liver Function Tests?**

About 25% of people went on to look at further pages on the **Lab Tests OnlineAU website** relatingto theLFT. When asked which pages or topics were visited, responses were varied.

* ***“Each individual chemical and what it was for.”***
* ***“Liver function tests.”***
* ***“Specific proteins.”***
* ***“Hepatitis.”***
* ***“Glossary of terms.”***
* ***“Results page - pretty useless without looking at the video - should put normal values on here as well.”***
* ***“About PSA testing, B12 Test results & Serum folate results. Cholesterol, HDL & LDL.”***
* ***“Not yet but I get a lot of blood tests, most I know about but there's always something new.”***
* ***“I'm a scientist and routinely access lab tests online.”***
* ***“I plan to as I have just found your website and it is very informative.”***

**Q7. Would you like to make a general comment on the information you need to help you when receiving tests results?**

There were many responses to this question. Some people referred to being generally confused.

* ***“Am often overwhelmed by the printout my doctor gives me. Too many numbers and I end up not attending to what the results mean! Your video was better!”***
* ***“I found this video extremely helpful. Explanation of LFT was very comprehensive and helped me a lot to understand the results. Unfortunately, I feel I do not get enough information from the doctor and this video filled that gap so well. Thank you.”***

Quite a few people were concerned about abnormalities - highs and lows.

* ***“What a high or low result may mean.”***
* ***“Knowing if the results are abnormal - clarify abnormal in what way? Too high, too low, what does it mean?”***
* ***“I would like to be able to understand the various items on the results sheet and where they sit on the expected ‘scale’.”***
* ***“It is good to know what the letters stand for and what this means in the context of your body systems. I found it useful to know what it means when certain results are both elevated.”***
* ***“Information about the difference in results and ranges used by different labs for the same tests.”***

Some people were concerned about understanding their test results over time – had they improved?

* ***“It is helpful to know more information about results, even results within the normal range. Like, is this result showing a change in health (reduced or improved, since the last test).”***
* ***“Need to be able to see trends over time, including results ordered from other labs/GPs/specialists.”***

Comments were overwhelmingly positive.

* ***"I think everything was explained very clearly in this video. I have a science background, so I felt comfortable watching the video and I am sure people without a science background can also understand this because it is visual and explains everything thoroughly and slowly.”***
* ***“Thank-you for making Australia a better place to live in. You might not know how scary and frustrating it is to live in a country where medical attention is hard to find. Thank god for Australia! I love it!"***
* ***“I think this is an excellent tool for helping the patient to stay informed and more collaborative in their care. It is also a quick organized review for healthcare providers approaching a counselling session with a patient.”***
* ***“The information provided on your website is very helpful in general, to understand what they are testing, and how the tests are performed. Sometimes however, my doctor fails to inform me if a test is fasting or not and providing this information is very helpful.***

***Thank you for all your website does.”***

**Q8. Overall, how useful do you find the Lab Tests OnlineAU website?**

**(Part B) Comments and Suggestions from Health Professionals**

Only a small number of our respondents identified their profession and the sector in which they worked. These were four GPs, four nurses, one allied health professional, six lab professionals, one student and two lab admin personnel.

Nine people worked in primary care, seven in specialist care, 12 in hospitals, four in day clinics, one in a research centre and one in a lab.

**Asked to describe aspects of pathology test results in general that their patients found confusing several responses referred to abnormal results.**

* ***“Significance of mildly abnormal results.”***
* ***“What is means when they are outside 'normal' reference ranges.”***
* ***“Normal reference range and specific requirements for blood tests such as dietary requirements or timing after a medication.”***
* ***“Reference Ranges.”***

Some related to specific tests

* ***“Troponin.”***
* ***“Iron studies, liver function tests.”***
* ***“Molecular.”***

Some were more general

* ***“Names and numbers.”***
* ***“All aspects.”***

**Asked about any key information that** **Lab Tests OnlineAU could** **provide that would help support the advice they gave their patients when they received their results (all laboratory tests), health professionals’ responses were varied.**

* ***“Maybe the video could have a bit more emphasis on outliers in reference ranges in healthy people. Also test preparation.”***
* ***“How a test is done and why it is necessary to e.g. fast before the test, wait 2 hours after taking a certain medication, etc.”***
* ***“Explain the basics of what each test reflects - which is what this video has done.”***
* ***“Why a test is ordered with specific examples.”***
* ***“Short, key information.”***
* ***“I am Canadian and we have been able to access our results online for over a year. I feel that having this resource (your vids) is a much more reliable source than googling what your results mean.”***
* ***“It's important that patients are not ‘overly’ alarmed as they look at their results on their own, so providing information in a way that helps them see the importance of context in interpreting the results. I think this LFT video did a good job in that aspect.”***
* ***“I think you already do; your site is fantastic and I've recommended it to dozens of health professionals and students as well as patients.”***

It was also suggested that we urge people to see their doctor

* ***“To go to your doctor, because he/she knows your clinical signs and symptoms.”***

**Looking at the LFT video in particular, respondents were asked to identify any information that stood out as being helpful. Again, their comments were varied.**

* ***“The narrator is not rushed and explains what each test indicates, but stresses that these results need to be interpreted by your doctor - good advice!”***
* ***“The explanation about individual liver enzymes and that ALP, AST etc. are not specific to the liver but come from other structures.”***
* ***“I like the way the different biomarkers were explained in view of clinical decision making.”***
* ***“It was very good - basic, not too long, not too much information. It was clear and the subtitles I think are helpful. Highlighting each of the tests and their relevance was excellent.”***
* ***“The moving highlighted table was great.”***
* ***“I think it's excellent overall and the language is fine for the layperson.”***

**Respondents were also asked whether there was information in the LFT video that would confuse patients.**

The large majority of respondents either did not comment or said ‘no, the video was clear’. Only a few respondents made comments.

* ***“No, I think it was simple and clear, some of the dialogue dropped out- esp. regarding ALP and bile duct.”***
* ***“Maybe not confuse but perhaps scare patients. It might be better to say 'severity' of damage to the liver' or say 'extent' or 'degree' of damage to the liver, so as not to scare people. Severity sounds like the word severe.”***
* ***“What do results mean for me?”***
* ***“No I think it is great for an average patient's level of health literacy and some people will have a higher degree of health literacy and they like more technical terms.”***

**Our health professionals were asked to identify any information missing from the video that they thought should be included.**

The majority of people said ‘no’ or did not offer any suggestions. Suggestions included:

* ***“You did not mention about family care and education. You also need to talk about the advice that professionals need to give to the family.”***
* ***“Perhaps mentioning Gilberts syndrome as a cause for elevated BR.”***
* ***“Ask your doctor for further information.”***
* ***“Clotting factors.”***
* ***“How the entire panel is run on the instrument and why certain conditions need to be met.”***

**People were asked how Lab Tests OnlineAU could best support them in helping their patients.**

* ***“Every time I come to your site, I am able to find what I'm looking for.”***
* ***“Encourage patients to comply with follow up of tests?”***
* ***“Yeah, sometimes I wish the information contained more about the normal reference ranges. I***
* ***wonder why you don't do that often but perhaps you have a legitimate reason legally?***
* ***“I find this site a huge help when doing my work.”***
* ***“Lab Tests OnlineAU is a great basic resource for patients with little knowledge of lab tests.***
* ***The Videos are already a good way to do that.”***

**Asked to say how useful they found the Lab Tests OnlineAU website overall.**

**Ninety per cent of respondents found the website ‘extremely’ or ‘very’ useful. Ten per cent found it ‘somewhat’ useful. No-one found the site ‘not so’ or ‘not at all useful’.**

**6. Summary**

The responses to the video from both consumers/patients and healthcare professionals are overwhelmingly positive and it clearly helped many people understand LFT results.

The pitch, language and amount of scientific information delivered appear to be at a level that reaches the majority of our audience. We recognise that some people will require more information (but they can find this elsewhere on the website), while others may not grasp everything being said (although they have the option of replaying the video if this helps them).

Therefore, it suggests we should apply this communication tool to other tests and possibly develop it further.

The responses also suggest that one of the key difficulties people have, not surprisingly, is relating their results to reference intervals or ranges. Many analytes vary between laboratories, and this has prevented us from providing this information on the website. However, given that some 25-30 analytes are now harmonised i.e. everyone in Australia is using the same range, perhaps we should show that information for those particular tests, and maybe provide some additional graphics to assist with their explanation?

It was gratifying to see that the large majority of responses to questions about Lab Tests OnlineAU more generally were extremely positive and affirm that we are providing an information service that is necessary, helpful and appreciated. Some of the responses served as a reminder that the people who use us are often at those times in their lives when they are highly anxious about their health.

Lab Tests OnlineAU is at a pivotal point in its evolution. Our study helps re-affirm that there is a clear need for a non-commercial, independent, trustworthy internet source of public information about pathology. Lab Tests OnlineAU’s role as the first point of reference for the public in My Health Record comes with increased responsibilities. To meet public expectations we must further develop and refine the information we provide, ensuring comprehensive coverage and innovative ways of delivery in our role as the Australian public’s primary source of pathology information.

**Addendum 2. LTOAU RCPA Pathology Update 2019 Poster**



**Appendix 3. LTOAU Infographic Summary June 2019**



