#### **Communication and**

#### LAB TESTS ONLINEUK

#### **Your Trusted Guide**

Peer Reviewed • Non-Commercial • Patient Centred

Dr Danielle B Freedman
Chair of the Board for Lab Tests Online-UK

Wegas 2018 Cardiff, UK

#### **Key Points**

- We need to improve the health of patients by increasing their understanding of laboratory tests
- Patients want to see their results how we, as professionals, can enable them to understand the results
- To empower patients and reduce the time needed to spend with healthcare professionals
- Improve clinicians understanding of laboratory tests!







#### Additional Patient Resources

Tests ▼ Conditions/Diseases ▼ Health Screenings ▼ Search Q

# Global Sites Send Us Your Feedback

#### 15 Country Sites in 13 Languages

In English	στα Ελληνικά	Po Polsku  www.labtestsonline.pl  Em Português  www.labtestsonline.org.br		
www.labtestsonline.org.au	www.labtestsonline.gr			
www.labtestsonline.org.uk	Türkçe			
www.labtestsonline.org	www.labtestsonline.org.tr			
En español	v češtině	中文版		
www.labtestsonline.es	www.labtestsonline.cz	www.labtestsonline.org.cn		
In Italiano	In Limba Romana	한글		
www.labtestsonline.it	www.labtestsonline.ro	www.labtestsonline.kr		
En français	Magyarul			
www.labtestsonline.fr	www.labtestsonline.hu			

#### Why do I need this blood test?

#### What does this laboratory result mean?

#### LAB TESTS ONLINEUK

**Your Trusted Guide** 

Peer Reviewed • Non-Commercial • Patient Centred

www.labtestsonline.org.uk

#### "Laboratory medicine empowering patients"







#### Additional Patient Resources

Tests ▼ Conditions/Diseases ▼ Health Screenings ▼ Search

#### Welcome to the New Lab Tests Online-UK

Send Us Your Feedback

The Lab Tests Online-UK website now has a new, modern design, with additional features. on the UK site and select global sites.

#### What's New?

Mobile-friendly design - easily accessible on a variety of mobile devices.

#### User-friendly layout of Test and Disease information

- · View comprehensive information all on one page.
- Use "Choose Topic" to quickly navigate to the information you want.
- · Find related topic content along with appropriate images.

Streamlined navigation - access the information you want quicker and easier.

Additional Patient Resources - quickly access content and feature articles on popular lab medicine topics.

**Popular Search topics** - visit the Home Page to access the most popular tests and related diseases searched by users. And find out about the latest laboratory medicine news and topics of interest.

Site users will continue to see new features and improvements rolled out over the coming months.

#### Lab Tests Online UK has a new Website!!

- Same information
- **Easier to navigate**



Tests

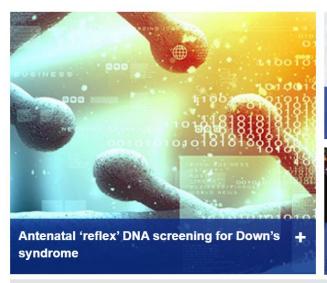


Conditions/Diseases

Health Screenings ▼

Search

https://labtestsonline.org.uk Antenatal 'reflex' DNA screening for Down's Additional Patient syndrome





View All News >



Could a new blood test help rule out a heart

Mobile friendly



WHICH? magazine



#### Additional Patient Resources

Tests

Conditions/Diseases

**Health Screenings** 



Search

Could a new blood test help rule out a heart

Q



attack more quickly?

Lab Tests Online-UK is recommended by GP's in + WHICH? magazine

View All News ▶

syndrome



#### Additional Patient Resources

Tests

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Conditions/Diseases

**Health Screenings** 



Search

#### **Patient Resources**





Send Us Your Feedback



Lab Tests Online-UK is designed to help you, the patient or caregiver, understand the what, why, and how of laboratory testing. To access the primary resources on this website, you can go to the full listings below:











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#### Additional Patient Resources

Conditions/Diseases **Health Screenings** Tests Search

#### **Tests Index**



17-Hydroxyprogesterone 17-OHP 17-OH progesterone

2 24 Hour Urine Protein 25-hydroxy-vitamin D (Calcidiol); 1,25 dihydroxy-vitamin D (Calcitriol)

3 3-ANCA

#### Additional Patient Resources

Tests ▼ Conditions/Diseases ▼ Health Screenings ▼ Search

#### **Index of Conditions**

2 A B C D E F G H I J K L M N O P R S T U V
W

Anaemia

2 21-hydroxylase Deficiency

Amenorrhoea

A Acidosis and Alkalosis

Acromegaly

Acute DIC

Acute inflammatory demyelinating polyneuropathy

Acute Renal Failure

AKI

Alcoholism

Allergies

Alzheimer's Disease

#### **Lab Tests Online-UK provides:**

Detailed descriptions of 302 laboratory tests

 Descriptions of 114 conditions and diseases, cross-referenced to the relevant tests

News on advances in laboratory testing

 Links to other relevant and useful websites that can help answer any further questions

#### Top ten tests











### LAB TESTS ONLINEUK

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### LAB TESTS ONLINEUK

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Average website hits per month 158,306

To increase patient understanding of laboratory tests empowering them to become active partners in their own healthcare'

#### **Links to Lab Tests Online-UK**

(existing or working towards)

#### Websites:

- NHS Choices
- Microtest
- DrDoctor

- UCLH OCS project
- Many More!!
- Welsh specialist virology unit
- Choosing Wisely UK

#### **GP** systems:

- TPP(System One)
- HealthFabric
- iSOFT

- InPS
- i-Patient
- OMNI lab
- Manage your health

#### Some comments from users 2017/18

- Nicely presented and well written. A good educational resource for a retired GP
- As a nurse just starting to learn how to interpret blood tests ..the site is amazing...love it. Thank you.
- Very helpful to be able to see differences between one test and another. I am noting INR kidney filtration rate potassium and blood sugar levels. Thanks for info.
- Excellent and easy to understand
- Loved the sumple explanations of what the test means, what it measures and what it can be used to indicate eg high ESR and inflammation
- Brilliant & reliable. The mobile app is excellent, too.

#### In 2017

Who uses	Patient, family		
the website?	Healthcare Pro		
	Other/net spe		

y member, friend 64% ofessional 15% Other/not specified 15%

of the website?

What do they think - Did you find what you were looking for?

> - Was it easy to find? Yes 74%

> > No 26%

Yes 63%

No 37%

Patients – would you recommend

86% Yes

this site to your family and friends? No 14%

76% Yes Healthcare professionals – would No 24% you recommend this site to a patient?

Where did	vou learn	about Lab	<b>Tests</b>	Online-	UK?

Search Engine 68%

Other website 24%

Friend/Colleague/Family Member 8%

Magazine/Newspaper 1%

#### **Promotional Display at:**

Doctor's surgery 66%

Hospital 24%

Laboratory 7%

Health Fair 3%

66% of visits are from search engines (primarily Google) with 23% from referral sites (primarily NHS Choices) and 11% from direct hits.



Sept 2017



## Feeling in control of your health records

Would you like a written reminder of what your GP said at your last appointment (the typical patient remembers only about 10%)? Do you want to be able to check that referrals have been made, and see

...see your test results from the comfort of your kitchen table?

Haughton Thornley surgery near Manchester (see p21), is doing just that. She believes that every patient should be able to do the same by accessing their health records online.

In fact, 92% of surgerles across
England now offer patients access
to records including test results,
medication and immunisations.
Some, like Ingrid's, offer full access,
including to consultation records
and correspondence.

Ingrid has a number of health conditions and at one stage had seven consultants. If one couldn't find her notes, then she could fire up the computer and show them.

So when she was told she needed a blood test, there was no need- she had the results of the one the GP had done just a few days before

When Ingrid travels, she can access her GP medical information from anywhere with an internet

And she can find out more about her condition, monitor it and have informed conversations with her GP in 'a partnership of trust'. That, says Ingrid, is how you get the best health outcomes.

Ask at your GP surgery to try these kinds of online services yourself.



#### Useful websites recommended by GPs

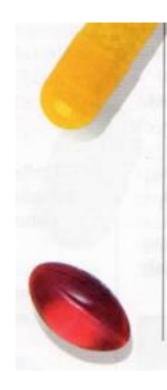
60 years ago, you might have dusted off an encyclopedia, but for nowadays here are five trusted websites that our GPs recommend to their patients:

■ Clinical Knowledge
Summaries – cks.nice.org.uk
How your GP reviews the current
evidence on how to treat you.
Technical but comprehensive.

Patients are recorded talking about their conditions, from atrial fibrillation to arthritis. Great for finding out what it's really like to have a condition

■ Lab Tests Online – labtestsonline.org.uk

Practising lab doctors and scientists explain your lab tests, from what to expect, to what the results mean.



#### ■ NHS Choices - nhs.uk

The huge NHS website includes comprehensive health information, service directories, and reviews and ratings of health and social care services.

■ Patient - patient.info

Started by GPs and now part-owned by EMIS, the computer system provider for GPs, it has just the right level of detail on health and medicines.







"It's interpret-your-own-test-results day today."



Annals of Clinical Biochemistry
International Journal of Laboratory Medicine

Availalbe online now Vol 53. No. 6 November 2016

Journal of the Association for Clinical Biochemistry and Laboratory Medicine, edited in association with the Nederlandse Vereniging voor Klinishce Chemie en Laboratoriumgeneeskunde and the Japan Society of Clinical Chemistry

#### Editor's Choice:

A survey of Lab Tests Online-UK users: a key resource for patients to empower and help them understand their laboratory test results

R Leyland and DB Freedman

10 1177/0004563216631774

Volume: 53 issue: 6, page(s): 669-679

Article first published online: March 24, 2016; Issue published: November 1, 2016

DOI: https://doi.org/10.1177/0004563216631774

## Who uses the Lab Tests Online-UK website?

Patients, their carers and health care professionals

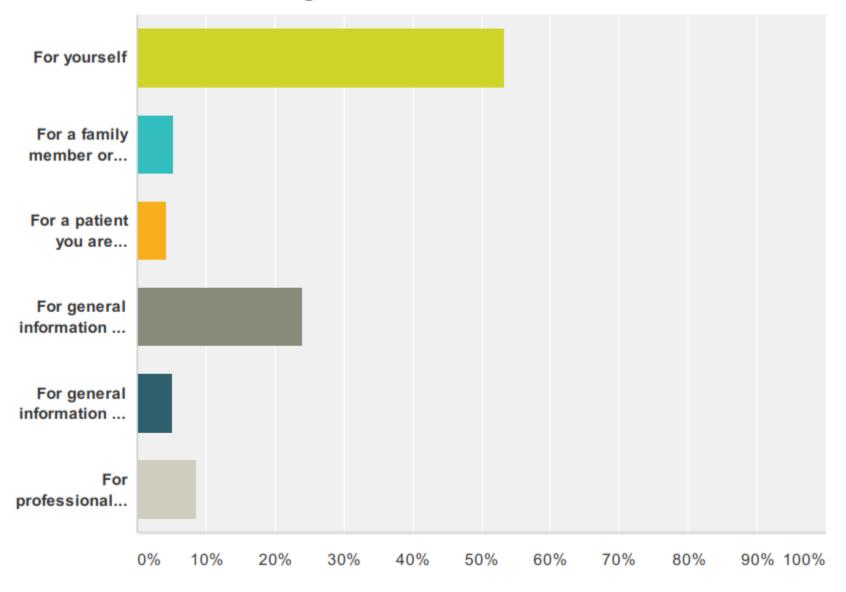
In our 2014 survey (661 responders):

- 40% of respondents were healthcare professionals
- 60% were patients or carers

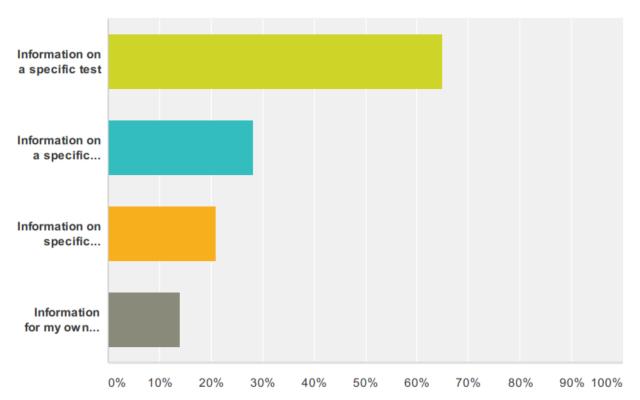
## **2014 Survey results Patients and carers**

- 71% found what they were looking for when visiting the website
- 71% found the information was written at the right level for them
- 93% found the information very easy or fairly easy to understand
- 87% understood their test/diagnosis/condition better after visiting our website

## Q3. Which of these best describes your reason for visiting Lab Tests Online-UK?



## Q 13. Which of these best describes what you are looking for today on this website?

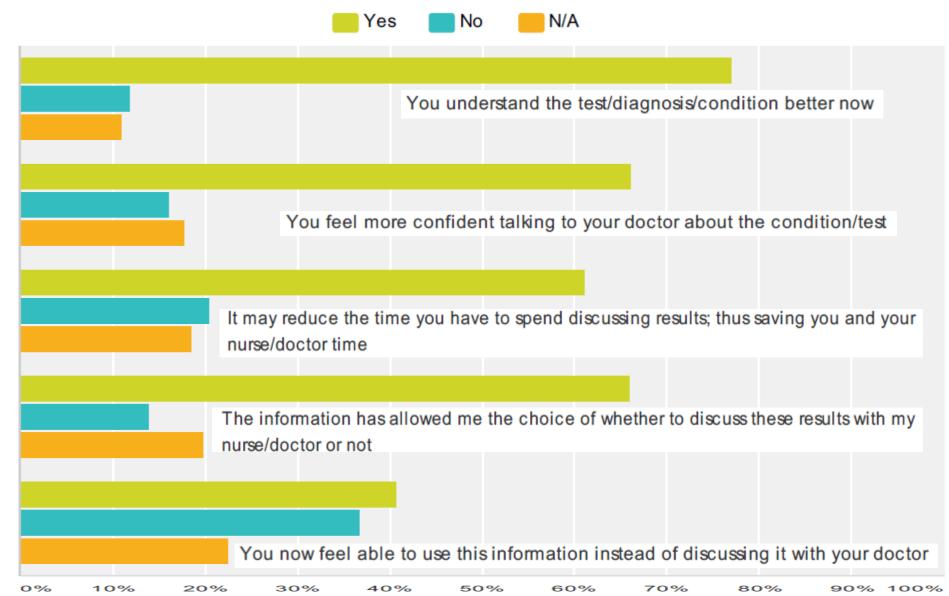


- I have been told my white blood count is low
- Doctors lack of time/complacency etc
- Trying to understand what raised white blood cells means
- My wife desires to know what poisoned her. Current doctors are monitoring her recovery but are not finding the source

## Q16. You stated that you did not find what you were looking for on the website (11%) Please could you state what was missing on the site

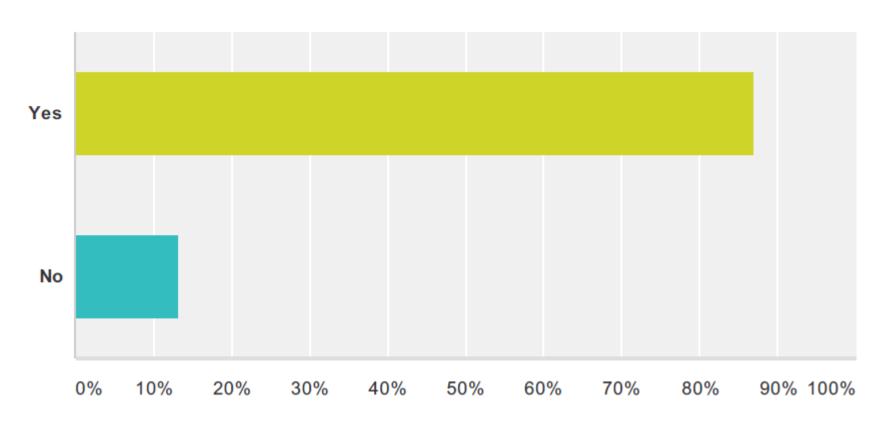
- I'm suffering from joint pain in my hands and feet and was wondering if this would be a consequence of taking statins over a period of years
- Wanted to find test results online
- Why I have high plate count
- What is a normal cholesterol
- I am suffering from a sewage leak over a year and want to test for ammonia inhalation if possible (local water board not repairing) and possibly other V.O.C.s Also any precautions or cures I need to take.
- Home testing for mercury
- Was looking to find out if HRT for menopause safe to take after radioiodine
- Testosterone cream for women

### Q20 Which of these statements applies to you as a result of using this website?



## Q21 Would you like to see (either by electronic access or on paper copy) your laboratory test results, at the same time as your doctor/nurse sees them?

Answered: 311 Skipped: 350



## Q23. Only 4% would NOT like to see their laboratory test results, at the same time as their doctor/nurse

## Please may we ask why you do not want to view your laboratory results

- They know how to interpret them, I'd just worry
- I wouldn't know what I'm looking at and it would probably make patient feel they know better than their GPs who are the experts
- Doctor can interpret the results, I can't
- Would not understand them. The consultant provides me with a copy of his letter to my GP. I therefore have info for discussion with GP

### Q28. In what ways, if any, could the Lab Tests Online-UK website be improved?

#### Please include any comments on the websites content and navigation

- By getting GP's to understand thyroid problems
- It's v good
- Excellent, doesn't need improvement
- Very good and informative website
- Site is easy to work
- Love it
- Great website, I recommend it anyone
- Excellent resource. Would struggle to find another resource online which is as comprehensive, useful and reliable at the moment.
- Indicate where one can get tested
- Normal range of each test to be mentioned
- LTO-UK website is well thought out, expertly presented website. Thank you for helping me.
- Lees muddle on home page. I did not bother to read it.
- The line of it being non commercial etc needs to be more obvious, its quite small to read yet it gives really important information

#### Summary / Key Findings

- 661 users responded but not all surveys were completed
- Liked / Loved website right level of information / very useful
- Patients WANT to see their lab results and want to know what they mean
- Professionals like the information right level
- Large number of users from outside the UK [Asia and America]
- Editorial comments: cluttered front page / font size
- Users unaware LTOL UK Team are working voluntarily
- App rated 4.35/5





#### Patient's view of the laboratory



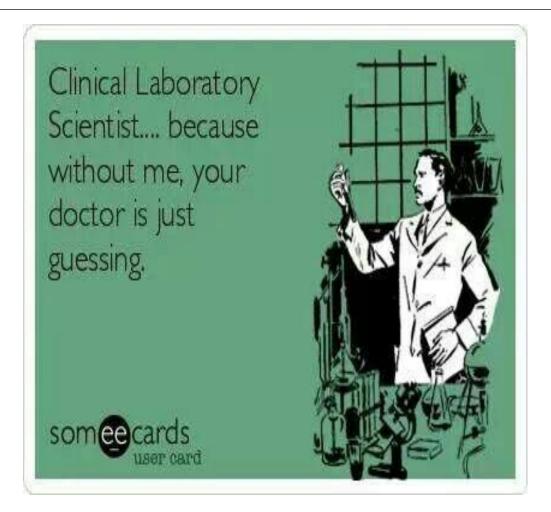


#### Other views of the laboratory





#### The reality



#### Head To Head

Head to Head

#### Can patients use test results effectively if they have direct access?

*BMJ* 2015; 350 doi: http://dx.doi.org/10.1136/bmj.h673 (Published 11 February 2015) Cite this as: *BMJ* 2015;350:h673

Article Related content Metrics Responses

Maurice O'Kane, consultant chemical pathologist, Altnagelvin Hospital, Western Health and Social Care Trust, Londonderry, UK, Danielle Freedman, director of pathology, Luton and Dunstable University Hospital NHS Foundation Trust, Luton, UK, Brian J Zikmund-Fisher, associate professor, Department of Health Behavior and Health Education, University of Michigan, Ann Arbor, MI, USA

Correspondence to: M O'Kane Maurice.OKane@westerntrust.hscni.net, B J Zikmund-Fisher bzikmund@umich.edu

Maurice O'Kane and Danielle Freedman say that patients welcome direct access to test results and that they improve clinic visits, but Brian J Zikmund-Fisher worries that the data are currently presented in ways that make them meaningless to most patients

Yes—Maurice O'Kane and Danielle Freedman

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#### Understanding your tests

Was this page helpful?

Q Search



#### UNDERSTANDING YOUR TESTS

COPING WITH DISCOMFORT AND ANXIETY

READING YOUR RESULTS

HOW SAMPLES ARE COLLECTED

WHY IDENTIFICATION IS IMPORTANT

TEST ACCURACY AND RELIABILITY

Having pathology tests can be a time of anxiety and uncertainty. Knowing what's ahead of you can make all the difference.

#### Your Role

One of the most important things in determining the accuracy and reliability of your laboratory test is you, the individual. After all, it is a sample from your body – blood, urine, or some other specimen – on which the test will be performed. Therefore, it is essential that you do the following to ensure that the results are useful:

- 1. Follow any instructions you are given to prepare for the specific test you are having performed.
- 2. Alert the person collecting your sample if you have not followed the instructions and in what way.
- Inform your doctor of any medications (including herbal remedies, vitamins and supplements) you might be taking or aby particular foods you have eaten within the day prior to the test.

Many tests require no special preparation but for those that do, be certain to keep to the instructions given. If you are unclear about the instructions be sure to ask your doctor for clarification.

Some of the more common types of preparation required for testing include fasting (going without all or certain foods) for



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#### Coping with discomfort and anxiety

Was this page helpful?

Q Search



UNDERSTANDING YOUR TESTS

#### COPING WITH DISCOMFORT AND ANXIETY

READING YOUR RESULTS

HOW SAMPLES ARE COLLECTED

WHY IDENTIFICATION IS IMPORTANT

TEST ACCURACY AND RELIABILITY

If undergoing pathology tests makes you or someone you care for anxious, embarrassed, or even difficult to manage here are some general tips on how to make the experience less stressful.

#### Know what to expect

Sometimes, undergoing an unfamiliar pathology procedure can turn out to be a tense, upsetting, or even frightening experience but with a little preparation you can help ensure that your test is as quick, painless, and accurate as possible. Emotional distress is more likely when your experience with a procedure does not match your expectations or you (or someone you know) have had a bad experience. Knowing what will happen is a good way to reduce this.

The pathology tests you are being asked to have are important in managing your health. Understanding why a test is being performed and how it helps your doctors can improve your attitude and preparation for the test. Being well prepared also helps you feel more relaxed and in control of the situation. Ask your doctor to explain the reasons for your test and how the test will be conducted. The information you will find under Tests and Conditions/Diseases on this website will also give you useful background information.



#### Reading your results

....reading the results can be confusing. Understanding what is normal and what is abnormal can be a little daunting.

#### Who prepares your test results report?

The pathology report is a medical document produced by the pathology practice. All pathology reports contains certain compulsory information that is essential for interpreting your results. Individual pathology laboratories often add their own information and they can vary in the way they present it.

Your tests will have been performed by scientists and/or pathologists. The pathologist-incharge who is a medical doctor who specialises in interpreting test results and observing and evaluating biological changes to make a diagnosis, will be responsible for your report. The pathologist is available to discuss your results with your doctor.

#### All that is red is not always abnormal

If in doubt, talk to your doctor as results need to be interpreted in the context of all the other information available.



### 'Better do a *few* lab tests...'



'I could give you a copy of your lab report but...

...I doubt you'd understand it.'

Language confusing FBC

LFT TFT



# Patient perspectives on test result communication in Primary care

Lichfield et al, BJGP, 1 Mar 2015

- Qualitative study 10 practices in Birmingham
- Focus groups of patients
- Pts preferred to receive results from Clinical staff, NOT receptionists!
- Frequent delays and inconsistency of:

level of information method of communication clear protocol

# Feedback from a patient with leukaemia using the LTO-UK website Sept 2016

I cannot find the right words to express my satisfaction with Lab Tests Online, particularly as the pages are embedded into my SystmOne Patient Online records. Being able to access test results without delays, being able to access information about each test, range information and other key details is absolutely wonderful........

She is now a patient LTO-UK Champion!

# "There for you all your life, your good health with our support, empowering you to live well"

#### **Haughton Thornley Medical Centres**

Haughton Vale PPG | Thornley House PPG | Search | Staff

gle™ Custom Search		Search	>
	powered b	ou Coogle	ai.

powered by Google " Thornley House Medical Centre 0161-367-7910

We are welcoming new patients. Please click here to join us now!

0161-367-7910 Out of Hours - GoToDoc 0161-336-5958

Haughton Vale Surgery

0161-336-3005

#### Latest News

NEW: Check if you are eligible for the flu injection. Dates for flu clinics out now! Read the Review of 2014 and what we need to do See the launch of Health Pledge 2015 At Clarendon Shopping Centre and Make a Health Pledge today! Donate to food bank URGENT: Learn about care.data and whether you and your family wish to opt out of sharing your data with 3rd parties without your consent



Welcome to our new Home Page which has been compacted to provide you with the most essential information for most of your needs as a patient.

The main website offers a great deal more information for those who wish to learn more about what they can do for themselves supported by a large number of resources we have gathered to support you and your family's needs.

If you or your loved ones would like to sign up for FREE online services then please click here.

You can send secure non-urgent messages online via EMIS Access or send an email about non-medical patters to htmcpatient@nhs.net

Common Problems



Appointment Health system Pledge



Main Home | Haughton Vale Medical Centre | Thornley House Medical Centre | Tameside and Glossop CCG | Health information in other languages | Terms and Conditions

Access to medical records

Understanding your test results

www.htmc.co.uk

Thanks to Dr.Amir Hannan

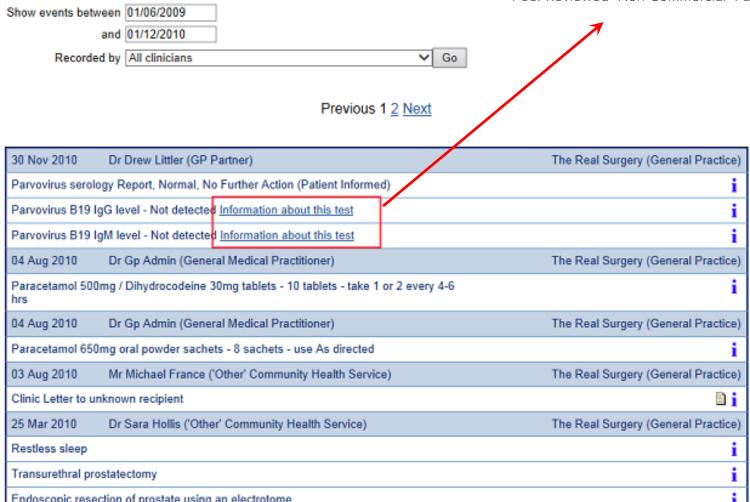


#### LAB TESTS ONLINEUK

#### Your Record (Page 1/2)

#### **Your Trusted Guide**

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# Guest blog: How giving patients access to health records can transform care - a GP's perspective

5<sup>th</sup> March 2018

- Patients at Haughton Thornley Medical Centres (HTMC) have been able to view their full GP electronic health record and gain a better understanding of their care for over 14 years.
- Currently 63% of all our patients have signed up.
- Patients are encouraged to go online and see their blood test results, using Lab Tests Online-UK to understand what they mean. And not have to book another appointment.
- Patients/carers are asked if they would like access to their full GP electronic health record as part of their care. This leads to shared decision making.
- Consultations are already changing from reading off the screen to spending more time planning for the future and gaining a shared understanding.
- Encouraging patients to be better prepared at sharing their data with others and more importantly share the knowledge gained.

## Understanding Patient Data

5<sup>th</sup> Mar 2018

# Guest blog: How giving patients access to health records can transform care - a GP's perspective Dr Amir

Dr Amir Hannan, GP

...A patient is **encouraged to go online** and see their blood test results, using <u>Lab Tests Online</u> to **understand what they** mean, as soon as they are available. And **not have to book another appointment just to find out it's normal...** 

...Our patients, and their carers, are **asked if they would like access to their full GP electronic health record** as part
of their care. This leads to **shared decision making**.... They
can become **active partners in their care**...



#### Patients' comments

...I have regular blood tests to monitor my medications. Checking online is an easy routine. The results are easy to understand with a link to "Lab Tests Online-UK" for further clarification...

...I can discuss the test results with the clinicians in the hospital departments who are involved in my prescribing so they have no need to repeat the tests...

...If I was waiting for some new results which may be upsetting or difficult to deal with on my own then I don't have to look. I can wait until I can discuss it with the support of the doctor...

I'm afraid I can't find anything wrong with you



surely that's some sort of syndrome in itself yeah?



# Online Self Diagnosis: Are You A "Cyberchondriac"?

Search engines can provide misleading information.

A report written in 2013 has revealed that an American spends on average an hour a week searching the internet for health information.

#### Self diagnosis can lead to unnecessary anxiety.

It's tempting to do your own research but leave it to the professionals.

However, if you really can't resist doing your own research, try these websites:

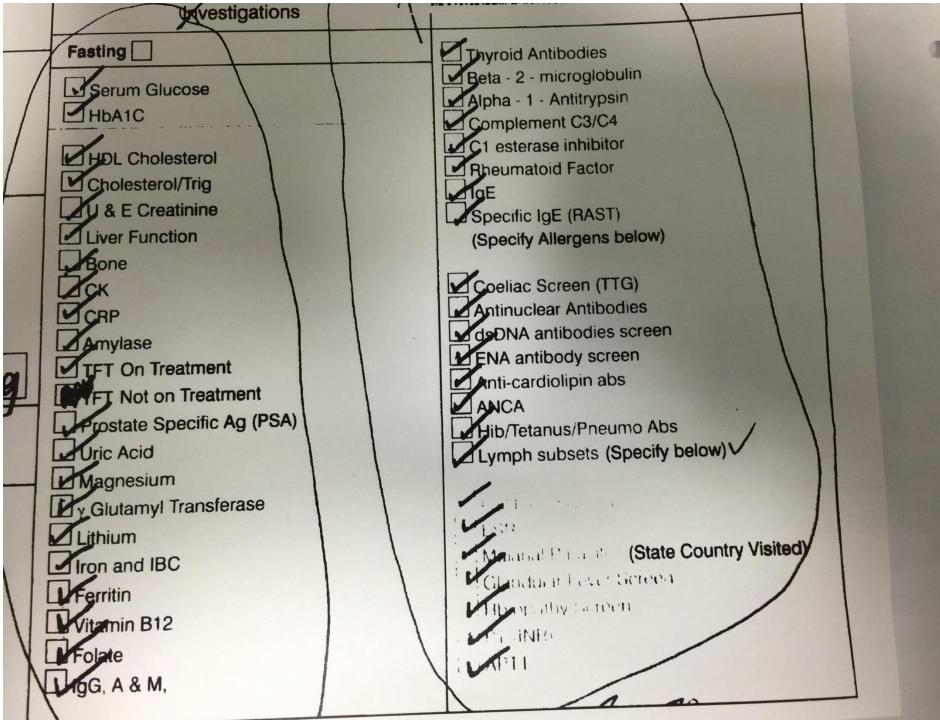
Patient.co.uk – this site is run by doctors where you can read leaflets on the condition and even seek medical support.

NHS Direct – This can help you narrow down the cause of your condition via a series of symptom checkers. You can also be referred to a GP

Lab tests online UK- This is written by practising lab doctors and scientists. This site can help you better understand the causes of medical conditions and the potential tests you could receive with a professional diagnosis. This site is also available as an app for smartphones.

#### The Problems

- Too many tests
- Different names
- Different units
- Different reference intervals
- Different alert limits
- Inconsistent guidelines

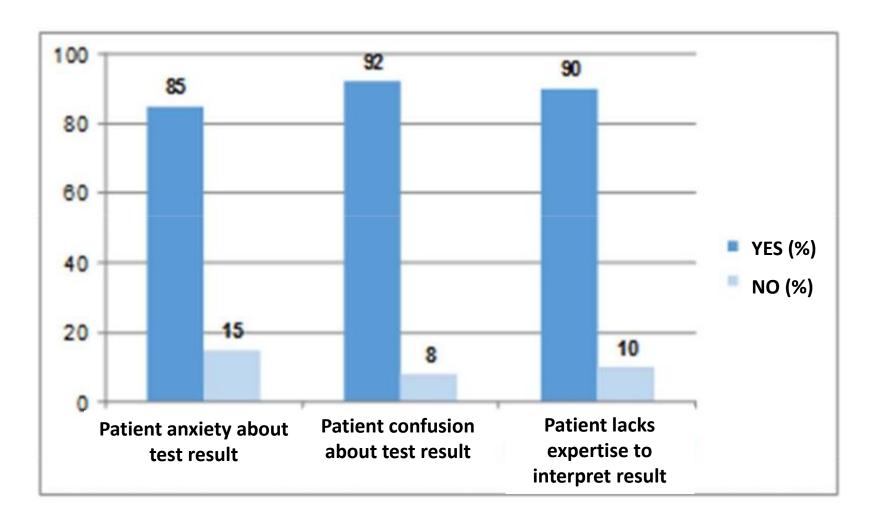


# Physicians perspective of releasing results direct to patients

Giardina et al, Patient Educ Couns, 2015 Feb 23

- US and Australia survey of GPs and Hospital Physicians
- 65.3% felt pts should be notified directly of normal results
- But 21.3% were comfortable with direct notification of abnormal results

# Main concerns regarding direct notification of results to patients



Callen J et al, J Med Internet Res 2015: 17 (3) e60

#### Evidence about the use of patient portals



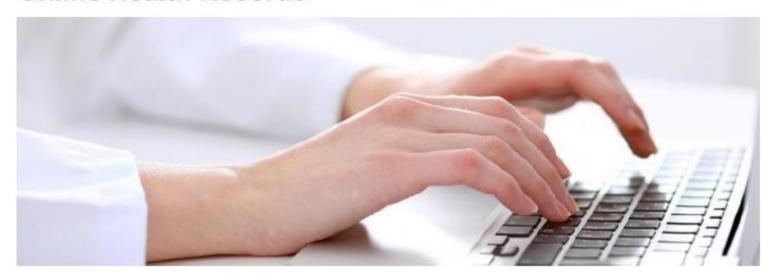




- Insufficient evidence about whether patient portals had a positive, negative or neutral impact (Goldzweig et al. Ann Intern Med 2013)
- Positive examples related to patients with chronic diseases eg diabetes and hypertension
- Very few studies have evaluated key performance indicators such as re-admissions, hospitalisations, length of stay
- We have only just begun to engage and understand this technology its effect on care delivery, outcomes and patient engagement



#### Patients Need Help Understanding Test Results from Online Health Records



February 8, 2018



This article was last reviewed on February 8, 2018. This article was last modified on February 8, 2018.

Online portals for laboratory test results offer a convenient way for patients to access their health information, and studies have shown that patients value that access. However, a recent study from Baylor College of Medicine, funded by the Agency for Health Care Research and Quality (AHRQ), shows



#### Study: patients need help understanding online test results

Baylor College of Medicine > Baylor College of Medicine News > Healthcare > Study: patients need help understanding online test results

Julia Bernstein Dec 2017

- Patients increasingly use online portals to access their test results
- But do they really understand what the results mean for their health and what steps they should take next?
- Researchers from Baylor College of Medicine conducted a study to explore patients' experiences and preferences when accessing their test results delivered to them via online portals.



#### Study: patients need help understanding online test results

Baylor College of Medicine > Baylor College of Medicine News > Healthcare > Study; patients need help understanding online test results

#### **Results**

- 25% who received a normal test result experienced negative emotions, such as anxiety, similar to those who received abnormal test results via the portals
- 50% of the participants *searched online* to figure out what their test result meant both in terms of the language and what it meant for their health. Thus, *materials that have been vetted by their physician or the healthcare system might provide patients with best resources*.
- Based on study data, researchers created a framework for practice and policy recommendations that can help guide the way the portals are developed and used.



#### Study: patients need help understanding online test results

Baylor College of Medicine > Baylor College of Medicine News > Healthcare > Study; patients need help understanding online test results

#### Lab Tests Online-UK already fulfils a number of the recommendations

- Ensure the portal is available on both *large-format computers and* hand-held devices.
- Provide patients with easy access to high-quality educational websites.
- Provide patients with *access to an explanation of test results* directly from results screen.
- Provide personalised or contextual information to help patients know what to do in light of the results.

Patient perceptions of receiving test results via online portals: a mixed-methods study. Traber D et al. Journal of the American Medical Informatics Association, 12 December 2017

#### Direct Release of Test Results to Patients Increases Patient Engagement and Utilization of Care

- 80% of all patient portal users viewed test results
- 82.7% noted test results to be a very useful feature
- Feel they should have direct access to test results
- Identified the ability to monitor results over time and prepare prior to communicating with a provider as benefits
- patient portal access to test results was highly valued by patients and appeared to increase patient engagement.
- "The more informed you are, the better you can handle and control your illnesses and diseases."

Pillemer F, Price RA, Paone S, Martich GD, Albert S, Haidari L, et al. (2016) Direct Release of Test Results to Patients Increases Patient Engagement and Utilization of Care.

#### Patient access to online services

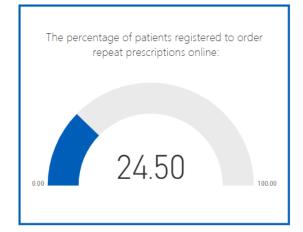
All GP practices in England, data from June 2018

#### Online appointment booking/cancelling:



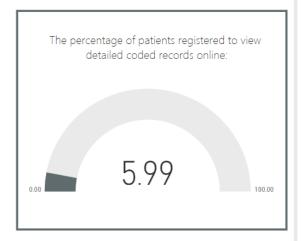
Number of transactions this month: **980K** 

#### Online repeat prescription ordering:



Number of transactions this month:

#### Online detailed coded record view:

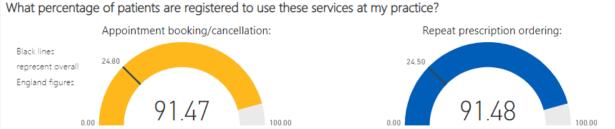


Number of transactions this month: 623K

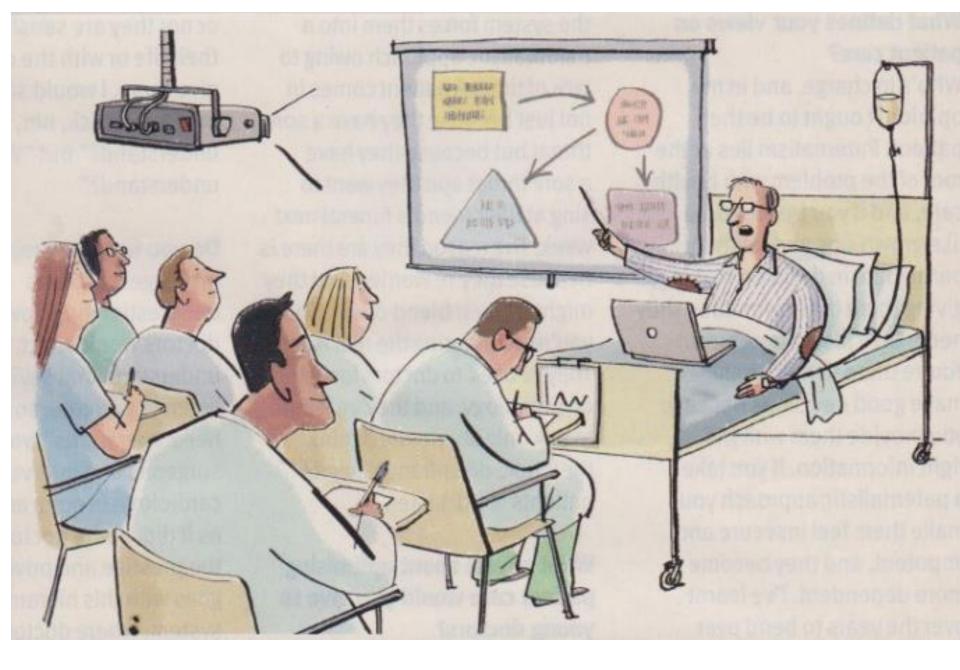
# When patient access to test results has a positive impact

#### **Haughton Thornley Medical Centre**

- Dr.Hannan proactively encourages use of patient online services
- Support for patients to use online services
- Support for patients to understand the information they are presented with – Lab Tests Online-UK
- Excellent patient and doctor satisfaction







# What the tests don't show Doctors are surprisingly bad at reading lab results. It's putting us all at risk

Washington Post, Daniel Morgan, Oct 5 2018. Daniel Morgan is Ass. Prof of epidemiology, public health, infec diseases, Univ of Maryland School of Medicine and Chief of Epidemiology at the Baltimore VA Medical Center.

- Every year, doctors in the US order more than 4 billion tests -my research has found that many physicians misunderstand test results or think tests are more accurate than they are.
- Doctors especially fail to grasp how false positives work, which means they make crucial medical decisions sometimes life-or-death calls based on incorrect assumptions that patients have ailments that they probably don't. When we do this without understanding the science of risk and probability, we unacceptably increase the chances of making the wrong choice.

Role for LTO.....

#### Direct Release of Test Results to Patients Increases Patient Engagement and Utilization of Care

F Pillemer et al. 2016 PLoS ONE 11(6): e0154743. doi:10.1371/journal.pone.0154743

**AIM**: Determine the impact of allowing patients to view their test results via patient portal in one large health system over one year period

**METHOD**: Mixed methods analysis of electronic health record data, surveys, and qualitative interviews over one year period

**RESULTS: 80%** of all patient portal users viewed test results

**82.7%** noted test results to be a very useful feature

70% patient portal has made their provider more accessible

**CONCLUSIONS:** Patients felt they should have direct access to test results

- Benefit -ability to monitor results over time, prepare before consultation
- Test results lead to unnecessary patient anxiety (patient and physician reported examples)
- Both groups noted the benefits of results released with provider interpretation.
- Overall portal access to test results was highly valued by patients and appeared to increase patient engagement

### Patient perceptions of receiving test results via online portals: a mixed-methods study

TD Giardiana. J Am Med Inform Assoc. 2018 Apr 1;25(4):440-446

**AIM**: Explore patients' experiences and preferences when accessing their test results via portals.

**METHOD**: Mixed methods study. 95 interviews with adults who accessed their results via the patient portal over a one year period

#### **RESULTS:**

**63%** did **not** receive any explanatory information or interpretation at the time they received the result

**46%** conducted online searches for further information about their result

Patients who received an abnormal result were more likely to experience negative emotions (56% vs 21%; and more likely to call their physician (44% vs 15%; compared with those who received normal results.

#### **CONCLUSIONS:**

Study findings suggest that online portals are not currently designed to present test results to patients in a meaningful way.

Patients experienced **negative emotions** often with abnormal results, but sometimes even with normal results.

Simply **providing access via portals is insufficient**; additional strategies are needed to **help patients interpret** and manage their online test results.

Given the absence of US national guidance, our findings could help strengthen policy and practice in this area and inform innovations that promote patient understanding of test results.

#### Role for LTO/AACC.....

### Patient's experiences of accessing their online electronic health records: National patient survey in Sweden

Moll J et al. J Med Internet Res 2018;20(11):e278

- Investigation of patient's experiences of accessing their electronic health records through the Swedish national patient portal, focussing on user characteristics, usage and attitutudes
- 5 month data collection in 2016 via patient survey
- 2587 users completed the survey, response rate 0.61%
- 72% used the online records portal once a month
- Main reason for access: gain overview of health status
- 98% respondents reported lab results were the most important information for them to access
- 87% reported positive feedback towards online records access
- Important reasons for respondents to access online records included: patient empowerment, involvement, security

#### Reasons for using the online results portal

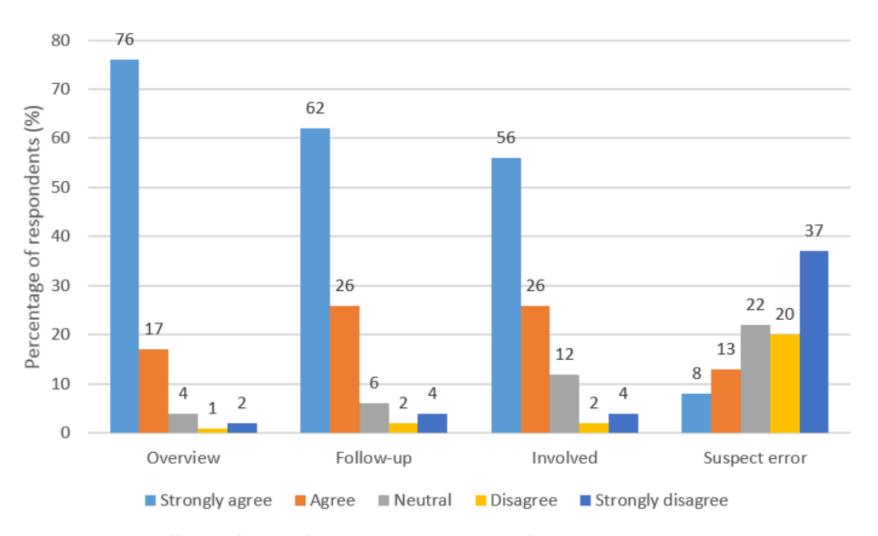
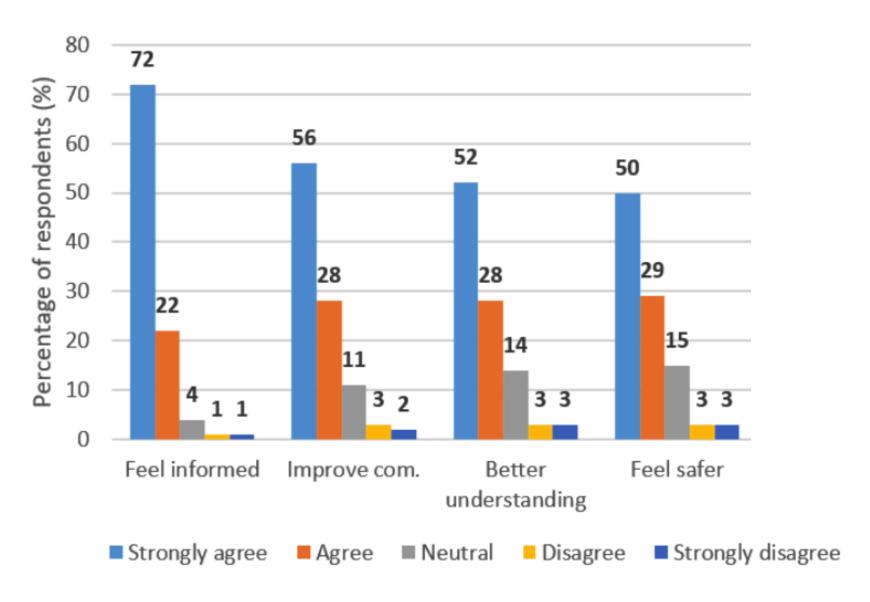


Figure 3. Moll J et al. J Med Internet Res. 2018. vol. 20:11. e278.

#### How using the online results portal makes respondents feel



Adapted from Figure 4. Moll J et al. J Med Internet Res. 2018. vol. 20:11. e278.



#### Cancer Taskforce Report - RCPath response

Roll out of the National Laboratory Medicine Catalogue and links to *Lab Tests Online* will support patient access but it is likely that senior pathologists and scientists will need to spend more time explaining results to patients, which puts pressure on an already stretched service.

carroon

The proposed new target of a definitive of 2020 is challenging but achievable if the equipment and organisation. As it talkincrease in training numbers is need target. In some pathology special trend that must be reversed.

diagnosis for 95% of patients within four weeks by ificant rapid investment in pathology workforce, ears to train a pathologist or scientist, an there are to be sufficient experts to meet the ainees has actually fallen in recent years, a

We are pleased to see the recommendate that this is developed it does with access to appropriate professional support and IT infrastructure. Roll out of the National Laboratory Medicine Catalogue and links to Lab Tests Online will support patient access but it is likely that senior pathologists and scientists will need to spend more time explaining results to patients, which puts additional pressure on an already stretched service.

#### Minimum standards for the display of test results to patients

Autumn 2018 – work in progress by ACB/RCPath

 No national standards and little guidance available for developers on how results should be displayed.

#### **Minimum standards**

- All numeric test results should be accompanied by a clear reference range (if available) and units for the analyte
- Numeric results that are outside the reference range should be clearly flagged as abnormal
- Where results have been transmitted from the laboratory with an interpretive comment this should be clearly associated with the test result
- Links to provide further information about individual tests should be embedded within the patient view.
   We recommend LabTestsOnline.org.uk as a reputable source of patient information on laboratory tests













11<sup>th</sup> May 2018





1,111 views

4

If you want to find out more about this specific test, visit:

https://labtestsonline.org.uk/

### LTO-UK has a new champion!

#### **Dr. David Warriner**

National Medical Director's Clinical Fellow, AoMRC Choosing Wisely Campaign

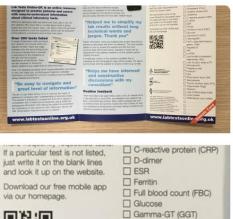
David recently (spring 2018) tweeted his support for LTO-UK



**David Warriner**@DrDavidWarriner

@LabTestsUK very happy
to be a LabTests champion
#toomuchmedicine
#preventingoverdiagnosis
#choosingwisely





☐ Haemoglobin

 ☐ HbA1c (glycated haemoglobin, GHb)
 ☐ Hepatitis B

\*NEW\* leaflets and posters LAB TESTS ONLINEUR LAB TESTS ONLINEUK Contact us: LAB TESTS ONLINEUK 1) Use the tick boxes to Lab Tests Online-UK Your Trusted Guide About us select the tests your Lab Tests Online-UK Peer Reviewed • Non-Commercial • Patient Centred Your Trusted Guide doctor has requested, if Informing ly by NHS laborato a test is not listed here, ☐ B12 / Folate and scientists and is liance with the patients about ☐ Bilirubin just write it on the blank voode. It is a non nmercial venture and ☐ Bone profile laboratory pport is generously provided by the non-commercial website developed and updated by voluntary NHS laboratory professionals which alters to increase patient updates and Calcium (Ca) speciation for Clinical Biochemistry and Laboratory Lab Tests Online-UK is a FREE online.org.uk 2) Look up the tests on fedicine, the Institute of Biomedical Science and the ☐ CA-125 tests Royal College of Pathologists. Cervical screening our website at Lab Tests Online is the global face of laboratory Cholesterol (Chol) medicine with websites in 15 countries, in 13 different labtestsonline.org.uk languages and has received over 325 million visitors since its launch. The website aims to provide easy to Coellac disease tests ams to increase patient understanding of ains to increase patient understanding of laboratory tests empowering them to become laboratory tests empowering them beatthcare. 3) Learn more about why Creatine kinase (CK) inderstand information for all to support a more productive dialogue between patients and healthcare ☐ Creatinine the test has been Information labeled about 1 ab C-reactive protein (CRP) active partners in their own healthcare. requested and what the **Get involved** D-dimer Become a local champion for Lab Tests Online-UK results mean. O eGFR Promote Lab Tests Online-UK in marketing materials: ☐ Full blood count (FBC) promote the site ☐ Glucose No obligation ☐ Gamma-GT (GGT · Quarterly newsletter v Vant to know me **FREE** patient leaflets LAB TESTS ONLINEUK Improving patient understanding Patient leaflets are available, see the picture below. The aim of Lab Tests Online-UK is to increase patient Peer Reviewed • Non-Commercial • Patient Centred When patients are having a blood test they can use this labt org.uk leaflet to tick off or write down the test they are having Do your patients ask about lab tests? partners in their own healthcare. Why they are being done? The website is intended to website, which they can do in their own time at their own What do the results mean? complement and not to replace a consultation with a healthcare professional, giving additional labtestsonlineuk@acb.org.uk or via the page on the Lab Tests Online-UK is a FREE, nonbackground information and commercial, online resource designed helping the patient to understand to provide patients and carers with the implications of test results on easy-to-understand information about LAB TESTS ONLINE clinical laboratory tests. personalised interpretive advice to patier Millions of laboratory tests are The site also contains articles about how performed every day in the UK, aboratories work, including how samples are processed, information on the concept idea about what is being tested of 'normal' and 'abnormal' results and the and what the results mean I ah idea of reference ranges. Information is also Tests Online-UK provides simple available on how laboratories are accredited answers to common questions. and monitored to ensure they provide a quality service and accurate, reliable results patient's convenience and at their own nace. "So easy to navigate and great level of information" Over 300 tests listed Positive feedback A range of laboratory tests are There have been over eighteen million visits to the UK A range of industratory tests are listed and patients can choose the ones relevant to them. Each page indicates why the test is being done, the type of sample that is required, a description of the website since it was launched in June 2004, and feedback from patients has been overwhelmingly positive practice nurses also find it helpful for their own limitations of the test and the possible significance of the fessional development and when talking to patients results. There are also answers to frequently asked questions and useful links to other resources. "Helped me to simplify and answering questions about testing. my lab results without Over 100 diseases are listed which require laboratory test "Helps me have informed and long technical words esults to help with diagnosis, monitoring and treatmen constructive discussions with Detailed information is provided for common conditions and jargon. such as diabetes, kidney disease and anaemia my consultant" Thank you" labtestsonii labtestsonline.org.uk labtestsonline.org.uk

Request leaflets and posters from the website or visit the Lab Tests Online-UK stand

#### 3 year objectives (2017-19)

- Continue to implement the business plan
- Increase annual traffic by at least 10% year on year
- Ensure that GPs have direct links from their surgery to LTO-UK website
- Monitor and assess LTO-UK impact in primary care setting.
- Increase links with other public facing websites, e.g. national health related charities and others
- Secure permanent funding to support these activities
- Work with GP and patient record system suppliers to further integrate LTO-UK into patient facing applications.
- Work with the ACB and RCPath to push for mandatory standards for systems that display test results directly to patients.



### LAB TESTS ONLINEUK

#### Your Trusted Guide

Peer Reviewed • Non-Commercial • Patient Centred

#### In collaboration and supported by







In affiliation with



### The Invisible Doctor



#### FIT testing patient experience



A patient with an early diagnosis of bowel cancer following a FIT screening test visited the lab to meet the laboratory staff performing the test to share his experience and his gratitude for the service

Thanks to:

Rebecca Powney, LTO-UK