



Prostate Awareness Road Shows

Event Guidance Manual



Registered No 1109385

Guidance Manual

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Introduction

This manual has been developed as a guide to groups putting on Prostate Health Awareness road shows including PSA tests using The Doctors Laboratory (TDL).

Background

The Graham Fulford Charitable Trust was formed by Graham Fulford late 2004 having had a very dear friend and a close relative diagnosed with prostate cancer. Sadly both lost their fight against this insidious disease having, like many, been diagnosed too late. Over the last 12 years the Trust has, worked closely with David Baxter Smith M.A, M.Sc., M.B, B.Ch.,B.A.O.,F.R.C.S. Retired Consultant Urological Surgeon .

The great advantages of using TDL are the speed of response of getting the result, the flexibility it gives in enabling regular events to be held in local communities and the fact it offers PSA Free To Total Analysis when required. It is essential to understand all such groups will have the full support of TGFCT (with the experience gained in holding in excess of 650 events all over the country) and David Baxter Smith. Please feel free to contact them at any time.

How To Get Started

1. Get together a group of like-minded individuals who would “like to make a difference” in this vital area of men’s healthcare. Prostate cancer support groups are a perfect example.
2. Discuss this matter via phone, email or post with any or all of the following:

Wendy Hodgkinson of TGFCT on:

Tel 07748 614753,

gfcharitabletrust@gmail.com

66B Smith Street, Warwick, CV34 4HU

Annette Wilkinson of TDL Pathology

Email: Annette.Wilkinson@tdlpathology.com

Tel 020 7307 7373

David Baxter Smith Retired Consultant Urologist

Tel 01562 882314 david.baxtersmith@btinternet.com

Keepings, 36 Middlefield Lane, Hagley, Worcestershire, DY9 0PX
3. Consider holding a “pilot” session in a suitable venue in your locality. Please note GFCT and DBS will provide full ongoing support and follow up of any “abnormal” letters resulting from this pilot. After the “pilot” session consider setting up an ongoing regular awareness programme. As a guide each test costs £15 to £20 depending whether the extra test of ‘Free to total’ is required.
4. Local charities such as Freemasons; Rotary and Lions are just 3 of the many sorts of organisations who may be able to help financially. Just ask around- you may be pleasantly surprised by the results! Moreover, you can have voluntary collections at awareness events to help fund future road shows.

How To Run a Road show

1. Locate and book a suitable venue and time. Please note the emphasis is now on checking the “Health” of your prostate. This should help alleviate some of the worries.
2. Advertise it – bearing in mind each test takes 3 to 4 minutes.
3. Organise a pool of helpers and trained operatives (Phlebotomists, Practice Nurses). You may have to at least reimburse expenses for the latter.
4. Liaise with TDL and GFCT to ensure you have sufficient Psa kits and literature stock to cover the session
5. Organise fund raising before, during and after the event to cover the cost of that and future sessions.
6. Give your helpers specific roles on the night (it may be worth swapping roles on an event by event basis so helpers become “multi taskers”). These tasks will include;
 - a) Greeting men as they arrive and explaining how it all works. Giving them leaflets about PSA testing and any supporting organisations (GFCT/ Rotary/Lions etc).
 - b) Getting them to read the ‘A Guide for Men Considering a Psa Test (PCRMP leaflet) giving them the Pro’s and Con’s of the test then if happy to go ahead to complete a PSA test consent form, ensuring its been completed legibly and signed.
 - c) Results will be analysed by TDL who will email the results to TGFCT. They will then post the relevant “Green”(normal result-but look out for any symptoms); “Amber”(close to the upper ”normal” level for a man of that age-recommended to have a follow up test in 3/6 months); or “Red”(abnormal-not necessarily meaning anything seriously wrong-but should certainly be followed up by a GP).

All men with Amber and Red letters are given the telephone number of TGFCT help line who will be available to offer advice or deal with any concerns the recipient may have.
 - d) At the end of the event collect up the samples and either post them in the pre-paid envelopes or get them collected by TDL if that’s more

efficient. Also collect up the completed consent forms and send via recorded next day delivery to TGFCT, 66B Smith Street, Warwick, CV34 4HU. Please note TGFCT will be following up the “red” letters after approximately 6 months and “amber” letters after approximately 12 months. This procedure has been very well received in the past.

Post Road show Activities

1. Ensure consent forms have been sent to TGFCT and samples to TDL.
2. Have a “debrief” meeting to discuss how the event went/how it might be improved etc. Plan future events with a mindful eye-as ever-on fund raising to cover them! You should expect each test to cost £15 to £20 per person. If those who can contribute £15-£20 do so, this means that the fund-raising can go much further!
3. Keep in touch with TDL and GFCT about how things are going on this initiative.

Conclusion

Working together we will drive up the number of cancer finds and equally importantly improve the quality of life of lots of men suffering from benign conditions which it is equally important to find and treat.

APPENDIX A – INCIDENTALS NEEDED TO RUN AN EVENT

MANUAL
GUIDE TO PSA TEST LEAFLETS (PCRMP)
GFCT CONSENT FORMS
TDL FORMS
LARGE ENVELOPE ADDRESSED TO TGFCT FOR CONSENT FORMS
RECEPTION DESK AND TDL OPERATIVE INFORMATION SHEETS
PROSTATE HEALTH INFORMATION LEAFLETS (CAN BE SOURCED FROM PROSTATE CANCER UK)
TISSUES, DISPOSABLE GLOVES, ANTISEPTIC HAND GEL, PLASTIC APRONS, DISINFECTANT SPRAY
MICROPORE/PLASTERS/COTTON WOOL BALLS
SHARPS NEEDLES DISPOSAL BOXES
RUBBISH BAGS
PENS
COLLECTION BUCKETS AND GIFT AID FORMS

Reception Desk

Please Read Carefully Before Commencing

- On Arrival Men Are Given A Pack Containing
 - Leaflet
 - Guide To Psa Test Leaflet (Pcrmp)
 - Gift Aid Form (If Using One)
 - Tgfct Consent Form
-
- Please Ask Them To Read The 'A Guide For Men Considering A Psa Test' (Pcrmp) Answering Any Queries They May Have And If Happy To Proceed Fill In The Consent Form
-
- They Are Then Shown To The Waiting Area

Tdl Operatives

Please Read Carefully Before Commencing

- When Ready Call Men Over
- Check Consent Form Is Filled In On Both Sides, Signed And Legible
- Take Sample And Follow Instructions As Per The Leaflet Filling In The Label And The Tdl Form To Go With The Sample
- On The Tdl Form The Patients Name, Date Of Birth And Current Date Should Be Inputed With Your Own Group Ref E.G Pcase/Warwick Lions. This Is So The Urologist Will Know Which Group/Event The Sample Belongs To
- Please Make Sure All Writing Is Legible

- Put Sample In The Pre-Paid Envelope With The Tdl Form
- Inform The Man He Will Receive His Result As Soon As We Can – Hopefully Within A Week Though This Is Dependant On The Work Load!
- Retain The Consent Form To Be Collected And Sent To Tgfct At The End Of The Session



A Guide For Men Considering A Psa Test

The Psa Test Is A Simple Blood Test Used To Help Detect Prostate Cancer In Its Early Stages Pc Generally Produces No Symptoms, So It Is Important To Diagnose The Disease Before Symptoms Arise And While It Is Still Potentially Curable.

A Recent Trial Suggests That Treating Pc May Significantly Prolong A Man'S Life. A High Level Of Psa (Usually 10Ng/MI & Above) Is Likely To Be An Indication Of Prostate Cancer And Should Therefore Prompt Further Investigation.

A Moderately Raised Psa Level (Usually 4Ng/MI & Above) (Dependant On Age) Means That Other Factors, Including Digital Rectal Examination, Ethnicity Family History, Prostate Volume, Psa History, And Free To Total Psa Ratio, Should Be Considered In Determining Whether To Send A Man For Further Tests Such As Biopsy.

However, In Three Quarters Of Such Cases, Further Tests Do Not Detect Cancer. There Can Be Other Reasons For A Moderately Elevated Psa, E.G. Urinary Infection, Enlarged Prostate Etc. And These May Need Treatment.

Prostate Cancer Is Not Always Aggressive Or Life Threatening. Even If Further Tests Do Detect Early-Stage Prostate Cancer, A Specialist May Not Be Able To Tell Whether The Condition Is Life Threatening Or Harmless. This May Make Treatment Choices Difficult For Both Patient & Clinician.

All These Factors Have Led To The Current Controversy Over The Value Of The Psa Test. However, The Uncertainties May Be Reduced By Men Having A Regular Test, Ideally On An Annual Basis.

Regular Monitoring Of Psa Levels Can Highlight Any Significant Or Gradual Increase, So That Even When The Psa Is Within The 'Normal' Range, One Maybe Alerted To The Need For Further Investigation.

THE GRAHAM FULFORD CHARITABLE TRUST

REGISTERED CHARITY No.1109385

CONSENT FORM FOR PSA TEST

YOU ARE REMINDED THAT BY DEFINITION THIS TEST IS ONLY AN INDICATIVE ONE. WE STRONGLY URGE YOU TO FOLLOW THE MATTER UP WITH YOUR GP IF ADVISED TO DO SO.

PLEASE PRINT IN BLOCK CAPITALS

FULL NAME.....

ADDRESS.....

.....

TOWN:

POSTCODE:

DATE OF BIRTH (DD/MM/YYYY): / / AGE:

PHONE

NUMBER.....

IF YOU WOULD BE HAPPY TO PROVIDE YOUR EMAIL ADDRESS SO WE CAN SEND YOU FURTHER INFORMATION OCCASIONALLY, PLEASE ADD IT BELOW. PLEASE PRINT CLEARLY:

EMAIL ADDRESS:

.....

HAVE YOU HAD A PSA TEST WITH THE GRAHAM FULFORD CHARITABLE TRUST BEFORE?

YES NO

IF YES, HAS YOUR ADDRESS CHANGED SINCE YOUR LAST VISIT?

YES NO

PLEASE CIRCLE:

WHITE - EUROPEAN / WHITE - OTHER / ASIAN / AFRO CARIBBEAN / MIXED RACE / OTHER

FAMILY HISTORY OF PROSTATE CANCER: FATHER / BROTHER / UNCLE / GRANDFATHER

FAMILY HISTORY OF BREAST CANCER: MOTHER / SISTER / AUNT / GRANDMOTHER

YOU HAVE HAD SEXUAL INTERCOURSE OR EJACULATED IN THE LAST TWENTY FOUR HOURS?

YES NO

YOU ARE CURRENTLY TAKING THE DRUG: PROSCAR /PROPECIA (FINASTERIDE)?

YES NO

YOU ARE CURRENTLY TAKING THE DRUG: AVODART (DUTASTERIDE)?

YES NO

YOU ARE CURRENTLY TAKING THE DRUG: COMBODART (DUTASTERIDE)?

YES NO

YOU HAVE TAKEN VIGOROUS EXERCISE IN THE LAST 24HRS (CYCLE RIDING ESPECIALLY)?

YES NO

All information supplied will be held by The Graham Fulford Charitable Trust and will remain secure and confidential. Your details will only be used in order to allow the charity to monitor any changes in the rate of velocity (change) in your PSA score and for research purposes and will not be passed on to any third parties or used for marketing purposes in accordance with the Data Protection Act 1998. Any information passed on to research organisations will be completely anonymised and will contain no personal information.

If you have any concerns regarding the above, please speak to a member of the charity staff who will be happy to discuss this further with you.



I Would Like To Have A Blood Test By Which The Level Of Prostate Specific Antigen (Psa) And Other Markers May Be Measured. I Understand That This Could Give A Doctor Some Indication Of Any Abnormality Within My Prostate Gland But That I May Also Need A Simple Clinical Examination Carried Out By My Doctor. I Understand That I Will Be Notified Of The Result And Advised Of Any Further Action That May Need To Be Taken. I Understand That Very Occasionally The Result Could Be Normal Even If My Prostate Gland Is Abnormal And That If I Have Trouble Passing Urine I Should Still Arrange To See My Doctor. I Accept The Charity Accepts No Responsibility For Any Action I May Take Following Receipt Of My Result.

Signature:

Date:

FOR OFFICE USE ONLY

TDL RESULT DATE SENT

AGE

SCORE

FREE TO TOTAL

RED, AMBER, GREEN



Sunday, 21 August 2016

GREEN PSA RESULT

«AddressBlock»

D.O.B : «PersonDate_of_Birth»

«GreetingLine»

PSA Total: «PSA_Total» (ng/ml)

Free-to-Total Ratio: «Ratio»

The result of your PSA blood test on «Date_of_Test» indicates that your Prostate Specific Antigen (PSA) level is as shown above; if the test result is greater than 1.5 the Free-to-Total Ratio is also shown. If you are taking Finasteride (Proscar or Propecia) or Dutasteride (Avodart or Combodart) it is understood the “true” value of your PSA could be approximately double that shown.

Whilst this appears “normal” within the guidelines outlined below, you should be aware that even with a normal PSA there is still a chance of having prostate disease. Therefore if you are having problems visiting the toilet very frequently, making several visits during the night, having to rush to the toilet urgently, waiting a long time to start, only having a weak stream, passing blood or experiencing incontinence you would still be advised to see your GP. In any event it is recommended that you have the test repeated at regular intervals, in consultation with your GP.

Mr David Baxter Smith

M.A., M.Sc., M.B., B.Ch., B.A.O., F.R.C.S.

Retired Consultant Urological Surgeon

Age-related referral values for total PSA levels as used by a number of leading NHS hospitals

Age Range	Green	Amber	Red
Under 50	Less than 2.0	2.0 - 3.0	Over 3.0
Under 60	Less than 3.0	3.0 - 4.0	Over 4.0
Under 70	Less than 4.0	4.0 - 5.0	Over 5.0
70 and over	Less than 5.0	5.0 - 6.0	Over 6.0

It should be noted that the levels used above are slightly higher than those recommended by the Department of Health (DOH), but slightly lower than those recommended by the British Association of Urological Surgeons (BAUS). For DOH levels visit www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf. For BAUS levels visit www.baus.org.uk





Sunday, 21 August 2016

AMBER PSA RESULT

«AddressBlock»

D.O.B : «PersonDate_of_Birth»

«GreetingLine»

PSA Total: «PSA_Total» (ng/ml)

Free-to-Total Ratio: «Ratio»

www.psatests.org.uk

The result of your PSA blood test on «Date_of_Test» indicates that your Prostate Specific Antigen (PSA) level is as shown above; if the test result is greater than 1.5 the Free-to-Total Ratio is also shown. If you are taking Finasteride (Proscar or Propecia) or Dutasteride (Avodart or Combodart) it is understood the “true” value of your PSA could be approximately double that shown.

You will see this result is “borderline” within the guidelines outlined below. You are recommended, therefore, to contact your Doctor for a follow-up test. We understand that some medications may reduce the level of PSA indicated in the test, and ejaculation within the 24 hours before the test or very vigorous exercise, particularly cycling, may increase the level. Infections of the prostate can also raise PSA levels.

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Under 60	Less than 3.0	3.0 - 4.0	Over 4.0
Under 70	Less than 4.0	4.0 - 5.0	Over 5.0
70 and over	Less than 5.0	5.0 - 6.0	Over 6.0

It should be noted that the levels used above are slightly higher than those recommended by the Department of Health (DOH), but slightly lower than those recommended by the British Association of Urological Surgeons (BAUS). For DOH levels visit

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www.psatests.org.uk



Sunday, 21 August 2016

«AddressBlock»

D.O.B : «PersonDate_of_Birth»

«GreetingLine»

PSA Total: «PSA_Total» (ng/ml)

Free-to-Total Ratio: «Ratio»

The result of your PSA blood test on «Date_of_Test» indicates that your Prostate Specific Antigen (PSA) level is as shown above; the Free-to-Total Ratio is also shown. If you are taking Finasteride (Proscar or Propecia) or Dutasteride (Avodart or Combodart) it is understood the “true” value of your PSA could be approximately double that shown.

You will see this result is outside the guidelines considered as “normal” for a man of your age in relation to the guidelines outlined below. It does not necessarily imply there is anything seriously wrong with your prostate, but you would be advised to see your Doctor shortly as he may wish to carry out a further lab test and a simple clinical examination. If necessary your doctor may refer you to a specialist for further tests.

You should be aware that some medications could reduce the level of PSA indicated in the test, and ejaculation within the 24 hours before the test or very vigorous exercise, particularly cycling, may increase the level. Infections of the prostate can also raise PSA levels. To speak to our help line please ring 01562 882314. You may need to leave a message so please leave your name and number.

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Under 70	Less than 4.0	4.0 - 5.0	Over 5.0
70 and over	Less than 5.0	5.0 - 6.0	Over 6.0

FOR MORE INFORMATION ABOUT REFERRAL LEVELS AND OTHER FACTORS AFFECTING PSA SCORES - PLEASE TURN OVER



Registered No 1109085

Red Letter Information Sheet

1. It should be noted that the levels used overleaf are slightly higher than those recommended by the Department of Health (DOH), but slightly lower than those recommended by the British Association of Urological Surgeons (BAUS). For DOH levels visit www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf. For BAUS levels visit www.baus.org.uk
2. It is generally accepted that 75% of all raised scores are not because prostate cancer is present but because of something like a simple urinary tract infection; benign prostate hyperplasia (BPH); prostatitis or indeed simply a one off high reading.
3. Given these statistics an early discussion with your GP and a repeat test seems sensible. Please take this information sheet with you.
4. The revised Gov.Uk Prostate Cancer Risk Management Programme (PCRMP) published on 29th March 2016 includes the following statement "Studies have suggested that reflex testing with PSA Isoforms, such as ratio of Free to Total PSA (f/t + PSA) for men with PSA values <10ng/ml (known as the diagnostic 'grey zone') could improve specificity and reduce the number of unnecessary biopsies". For full details of the PCRMP please visit www.gov.uk/government/publications/prostate-cancer-risk-management-programme-psa-test-benefits-and-risks
5. A "Free to Total Ratio" is a more refined PSA test.
6. The Graham Fulford Charitable Trust statistics, based on over 60,000 tests carried out across the UK between 2004 and 2016 fully support this statement and in over 88% of more than 650 cancers found to date where Free to Total ratios were available, the ratio was less than 18%. The Free to Total test is a simple, inexpensive blood test. The benefits of having such a test should be discussed with your GP.
7. Since there are downside risks of having a prostate biopsy, in addition to determining your Free to Total ratio we believe you may want to discuss with your GP/specialist other available possible prostate cancer indicators including such things as an MRI scan BEFORE embarking on prostate biopsy.
8. There is now a wealth of information available on the subject of Prostate Cancer. The following are just a few links you might like to follow:

psatests.org.uk

chaps.uk.com

prostatecanceruk.org

www.cancerresearchuk.org

tackleprostate.org