

# East Lancashire Prostate Cancer Support Group Newsletter



Volume 7

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## *PSA Testing Event Saturday 23rd June 2018 @ Burnley FC “Turf Moor”*

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TESTING DAY | [@BKPCAppeal](https://www.facebook.com/BKPCAppeal)

is set to host another prostate cancer testing day at Turf Moor.

On Saturday, June 23rd, between 10am - 1pm, PSA tests will be available for men over 50, or 45 if cancer is prevalent in their family, at a subsidised cost of £5.



# General Data Protection Regulations (GDPR)

## Guidance notes for Support Groups

GDPR's main concepts and principles are much the same as those already in the current Data Protection Act. So, if you are complying correctly with the current law then most of your approach will remain valid under the new regulations. GDPR does not replace The Data Protection Act, it is an enhancement to the current law to offer greater protection and rights to an individual.

There are several new elements, some things you will need to do for the first time and some things differently.

### **What is the GDPR**

GDPR (General Data Protection Regulation) is a regulation that takes effect in May 2018. It aims to provide people with better control over their personal data, placing a greater emphasis on organizations' responsibility to provide choice and to keep better records of how they use the data they hold.

The GDPR places greater emphasis on the documentation that is held, which must be kept to demonstrate accountability. You should make sure that key people in your group are aware that the law is now changing – such as secretary, website and newsletter distributors

How will this apply to our group?

GDPR will change how you collect and store data.

It doesn't mean you can't contact people about your group or activities.

### **Key Changes**

You will need to tell people how and what you do with their data, at the point of collection.

You must ensure you gain written consent 'silence' is not enough.

You must consider how long you plan to retain their data and inform people how long that will be. Your policy should indicate what is a reasonable length of time to do so, in particular when an individual no longer engages with your group.

### **Preparation**

Process – understand the journey personal data takes through your group.

Awareness – make sure everyone in key roles understands the new requirements.

Policy – make sure your policies and practice reflect the new regulations.

Communication – ensure individuals understand what you are doing with their data.

What do we need to do?

### **Step 1**

The Process: Have a simple document that explains:

What data you collect (names and addresses etc.).

Where and how it is stored and who can view it.

Give people a copy when they opt in. Such as at their first meeting. In the case of existing members, a one-time only review is needed to check that the correct form of consent is held or obtained.

## **Step 2**

### **Consent:**

Have a consent form that asks for permission to store name, address and email details.  
This is the 'opt in' or consent policy.

## **Step 3**

Their rights. Make sure they have the right to:

Be removed from the list.

See what information you store (on them).

Have history deleted (theirs).

Change details.

### **What does consent mean**

Consent must be freely given, specific, informed and unambiguous.

There must be a positive opt-in.

Consent cannot be inferred from silence, pre-ticked boxes or inactivity.

You must have simple clear ways for people to withdraw consent such as by email or withdrawal form.

You are not required to automatically 'repaper' or refresh all existing Data Protection form consents but if you rely on individuals consent to process their data, make sure it will meet the GDPR standard on being specific, granular, clear, prominent, opt-in, properly documented and easily withdrawn.

## **Access and Storage**

You must let people know who will have access and why.

Make sure any data is safely stored, if electronic on a computer that the latest software/ security software installed and if possible encrypted (most systems have this as an option).

How you store their data and the security of it are your only real legal issues and by keeping a regular watch on your systems to ensure they are up to date will meet this requirement.

## **Further Information**

NCVO (National Council of Voluntary Organisations)

<https://www.ncvo.org.uk/>

ICO (Information Commissioner Organisation)

<https://ico.org.uk/>

## Privacy Statement

ELPCSG as a charity collect, store and use personal data such mobile contact numbers, email addresses and computerised information to keep in touch with our members and distribute relevant news or information about forthcoming events.

We take our duty to protect your personal information and confidentiality very seriously and take all reasonable measures to ensure the confidentiality and security of personal data for which we are responsible.

### **How do we collect information about you?**

We keep records about your contact details. These records help to ensure that you are kept informed about ELPCSG activities and relevant events or information. They may be written down in paper records or held on computer.

It is essential that your details are accurate and up to date. To enable us to do this please check that we have your correct personal details and inform us of any changes as soon as possible.

### **Who do we share personal information with?**

Your details are only used by FOPs secretary and support group team. Everyone involved in FOPs as a trustee or ELPCSG support group team has a legal duty to keep information about you confidential.

**We will not disclose your information to any other third parties.**

### **How your personal information is used to improve the service we provide.**

Your information may also be used to:

1. Contact you via email or
2. Telephone once you have signed to say you agree for us to do this.

### **How you can access your records?**

The Data Protection Act 1988/The EU General Data Protection Regulations give you the right to access the information we hold about you on our records. Requests must be made in writing to ELPCSG. We will provide information to you within one month of receipt:

## CONSENT FORM

Due to the new General Data Protection Regulation (GDPR), **East Lancashire Prostate Cancer Support Group** won't be able to contact you after 25th May 2018 with our latest newsletters, details of events - unless we have a "yes" from you.

By giving us your consent, you will continue to receive information and updates about after 25th May 2018. You will be able to hear from **East Lancashire Prostate Cancer Support Group** in the way you want to - by post, e-mail or phone, and you can change your mind at any time.

If you don't respond to us, you could miss out on hearing what **East Lancashire Prostate Cancer Support Group** is getting up to.

Give us your "yes" today

Full Name ----- \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Contact Number \_\_\_\_\_

Email Address: \_\_\_\_\_

Give us your "yes" to receive communication from us via the following: \*

Post  Phone  E-mail

What would you like to hear about? \*

Newsletter  Fundraising Events  Meetings

**Minutes of Meeting 87, – Thurs 3<sup>rd</sup> May 2018**  
**Mackenzie Centre Burnley Gen. Hospital 2 – 4pm**

**Present:** 24 people (including partners) and our Specialist Nurse Debbie:

Apologies: J Heyworth on holiday, Dave & Pat & Colin O.

Dave opened the meeting by explaining about having to close the doors at 2.30 pm, so if anyone comes late they need the Chairman's Tel. number or other numbers so that we can come down and let them in.

He read out the Minutes of the last meeting and one of the matters arising was the proposed donations to the Chemotherapy unit at Burnley General Hospital and the Urology Unit at Blackburn. They both do not know what they need at the moment so we have discussed giving a donation to Prostate Cancer Support NW.

At this point Colin Stott spoke about PC NW and the PC Federation and explained that it is a patient led organisation and told the group a little bit about this worthwhile cause. Colin read out why it is a good idea to take out membership of the Federation. We discussed if we could put this on our website. He gave us a leaflet which explains why it is a good idea to join. Another possible donation was discussed for The Cycle to the Moon project. Colin informed us that the Bolton Group are doing bike rides for it and suggested maybe we had some cyclists who could raise money that way!!!!!!

There is to be an AGM of the Prostate Cancer Federation - Tackle (designated Healthy Body, Healthy Mind). This is to be held at Birmingham on 12<sup>th</sup> June 2018 at 10.00 am. Dave wanted to know if anyone was interested in going.

A few of the events which are coming up in June when our Prostate C. information stand is needed, are a talk at Safron Nacelles Limited in Burnley, the Classic Car Show, an Art Exhibition at The Inn at Whitewell and the Blood Testing Event at Burnley Turf Moor on Sat 23<sup>rd</sup> June. It is hoped more information can be given at the June Meeting.

Debbie our Specialist Nurse explained how much Cancer Treatment has changed over the last 10 years – concentrating on active surveillance + MRI Scans. Colin spoke a little about the new MP MRI Scans and Debbie then gave information on the new diagnostic procedures that newly diagnosed patients can expect in the Lancashire Area.

**BREAK FOR BREW – RAFFLE MADE £26.00 + £3.50 donation**

In the 2<sup>nd</sup> half Dave informed us that John Heyworth will no longer be on the Committee and that Peter Chadwick will join in his place.

At this point Dave told how he had attended a Prostate Meeting in Los Angeles and had asked if he could take pictures. He was not allowed and they even have a facilitator who tells the group what they can say and what they can tell people! We like our informal meetings and hope our members are always kept informed.

At this point – in the absence of a speaker – we then played a radio article which was supplied by David H. who had managed to tape it and it was very interesting and informative about Prostate Cancer.

Dave closed the meeting with one of his famous prostate jokes and a reminder that the next meeting is 7<sup>th</sup> June in the McKenzie Centre at 2.00 pm.

*Yet Again We Will Be Manning The  
Prostate*

*Cancer Awareness Stand At The  
Burnley Classic Vehicle Show*

*Sunday 24th June 2018*

*Towneley Park*

*Burnley*

*Come & Have A Great Day &*

*Admire Some*

*Classic Machinery*



## Contact Information

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From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an