

# BEST FOOT FORWARD

CARDIAC & PULMONARY REHABILITATION PATIENT & PUBLIC INVOLVEMENT GROUP'S NEWSLETTER

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## Welcome

Welcome to our first ever edition of the Cardiac & Pulmonary Rehabilitation Patient and Public Involvement Group Newsletter. The editorial team (members of the group) aim to produce two to three of these a year, with the intention of updating the community on relevant rehabilitation activities.

## Who we are and what we do

We are a small group of patients and members of the public who are all volunteers and have been invited to be part of the PPI group (Patient and Public Involvement) to bring our first hand rehab experiences to a number of research projects.

These are aimed at improving and building the best programme of rehabilitation to help cardiac and pulmonary patients have a better long term recovery, and in turn, have a more promising future.

Now how we set about achieving this goal depends on the group members engaging with each of a number of real time research projects skilfully put together and led by a number of Glenfield's progressive and inspired doctors, nurses, physiotherapists, researchers and other medical staff.

Our job is to look over the shoulders of those conducting this important work to ensure two things;

As patients and members of the public we add to the research mix by keeping the projects and their leaders in touch with the reality of our practical patient rehabilitation experience and those of our colleagues.

Inform by a variety of media of the progress and development of this important work.

The work is demanding and challenging but will bring enormous benefit to those who have either cardiac and/or pulmonary illnesses.

Rehabilitation is a vital tool in the long term recovery of not only Glenfield hospital patients, but patients in general, that is why as a group we are working with the expertise of the medical

staff through these research projects to ensure a better patient understanding of this vital part of their recovery, which ultimately will lead to a better and improved standard of life.

All our efforts will be in vain if we fail to find and put the results of these projects across to patients in an informed and understandable way. This first newsletter sets out to do just that starting with a summary of just some of the many projects we are currently working on and who is involved.

John Hawkes – PPI Member



**CLAHRC**

Leicestershire, Northamptonshire  
and Rutland (LNR)

**NHS**

National Institute for  
Health Research



# What is Pulmonary Rehab and Why?



Pulmonary Rehabilitation is proven to be beneficial for people with Chronic Obstructive Pulmonary Disease (COPD) and other chronic respiratory diseases.

It will not heal your lungs but it will help you to be able to

do more e.g. walking and daily tasks. It consists of an exercise and education programme. Treatment is tailored to each person.

How will it benefit me?

Pulmonary Rehabilitation aims to:

Reduce your levels of breathlessness

Help you to improve your general health and level of

fitness

Improve your ability to carry out the daily activities that are important to you

Educate you about your condition

Help you to control the symptoms of your condition



**"My life has changed, and because of what rehab taught me I am a very confident, busy and happy lady." Pat Brickley**

## Hot news — PPI celebration

The great, enlightening role of the "Cardiac & Pulmonary Patient & Public Involvement Volunteer Deputy".

We represent the group at CLAHRC (Collaboration for Leadership in Allied Health Research and Care) Rehabilitation meetings at various levels and then feedback developments to the PPI group. We will take any ideas and suggestions generated by this group, to further CLAHRC meetings or conferences.

We attended a recent Health Research Fair hosted by Glenfield hospital, where ground-breaking developments in cardiac and pulmonary research were presented to the members of the research community, patients and PPI



**Poster display**

members.

Our PPI members Chris Brough and

Jonathan Mansfield demonstrated the Google based solution, with website and email facilities which they have developed as a communication device for use by the PPI group and hospital.

Dr Louise Sewell demonstrated the "Little Acorns" developments they have made to smart phone applications. This enables patients to be guided and to monitor their activity rates as part of their post pulmonary exacerbation rehabilitation process. These ideas look ripe for development for cardiac and diabetic patients too.

A "Blood to brain" in stroke patients presentation showed a new device for monitoring the blood flow to the patient's brain both when at rest and in vigorous exercise. It will enable medical staff to monitor and influence the auto regulation mechanisms in the brain, to the benefit of stroke patients.

"Life map" is a heart defibrillator type device which is implanted into patients deemed to be at high risk of suffering from a fatal cardiac arrest. Patients with a certain genetic condition are at risk, even though they may never have shown any indication of cardiac problems.

Finally, an in-depth presentation



**PPI members: Jonathan Mansfield, Mick Vose, Maddy Alton, Pat Brickley & Gemma McCarthy**

about the effects of obesity, pregnancy, diet, exercise and other factors on renal filtration rates and causes of blockages in the kidneys, highlighted the need to take care of all of these factors. The importance of having healthy kidneys and the detrimental effects of kidney disease was most enlightening.

When we reported back to the PPI meeting in March, the members reflected how useful the PPI group work is to the field of Cardiac and Pulmonary research and patient rehabilitation.

Now we all like the taste of that!

Maddy Alton — PPI Deputy



## Members Profile: Glynn Finney

My name is Glynn Paul Finney and I'm 37, I was born with a inherited Bronchiectasis and Asthma which now comes under the category of COPD which is easier to remember than the other mouthful.

As I've had the condition all my life I don't let it get to me I enjoy working with computers which was my chosen field from leaving Western Park Open Air School, & my hobby of amateur radio but still have to remember sometimes that it is there and that it makes itself noticed at such acquired times. The main triggers are smoky environments, cold spells but also hot weather and food/pet allergies.

In late 2010 I was encouraged to exercise with cycling and weight-lifting tasks. I began a daily hour of exercise. It really tired me but I

felt good. I had a focus and promised to continue.

I later attended a pulmonary rehabilitation program at Glenfield Hospital. With encouragement from fellow patient, Pat Brickley I improved and graduated to my local gym. Previously, I could only walk 250 yards before I was tired, now, on a good day I can walk 2.5 miles!

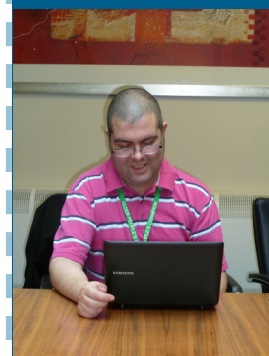
Although I do notice the condition more I still like to push the boundaries and have a go. The pulmonary rehabilitation program meant I gained my independence back again. My confidence is still lacking in some areas but that is something I'm working very hard to get sorted out.

My work with PPI is one giant move forward. The invite from the rehab team to be part of this group makes me feel proud

that people respect my knowledge and views for once. My mobile app idea for pulmonary rehab patients is also important to me & I was surprised when the idea was put forward as something of use to others.

In 1995 I graduated in IT and for 17 years I've sat in front of my computer at home in my room wondering what I could do as my health was so bad.

Now look at me..... AMAZING!



**Glynn Finney**  
Pulmonary Rehab  
PPI Volunteer

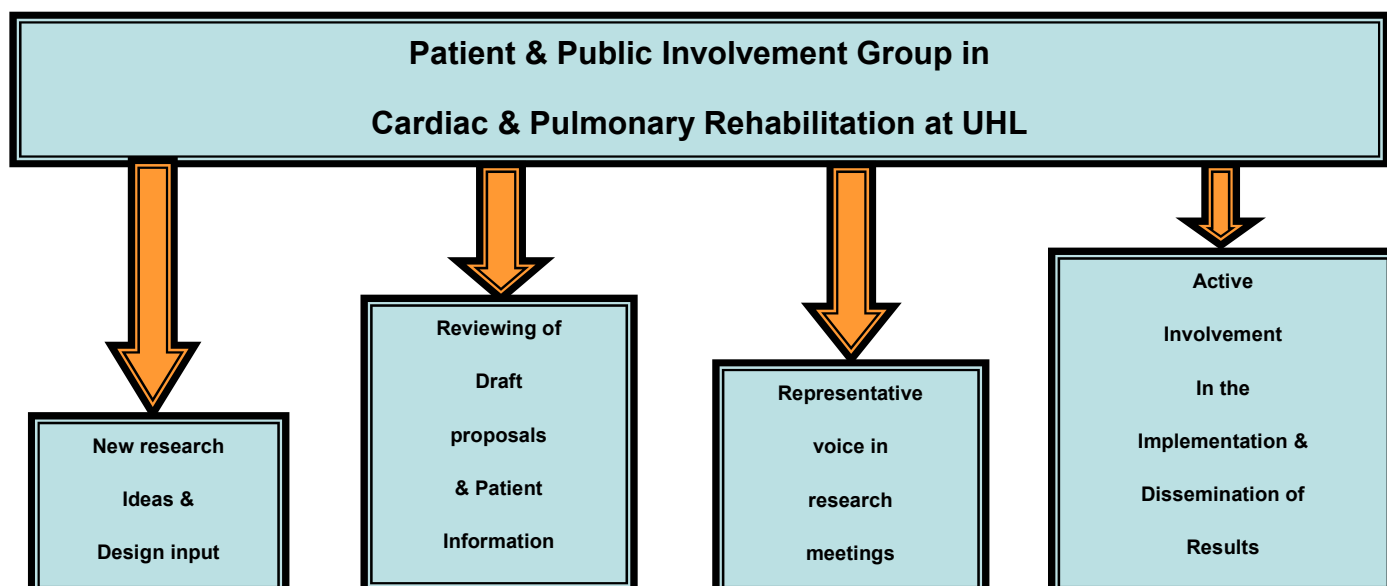
## PPI Involvement

All of our PPI members are involved in different trials, they are responsible for contributing to these projects from start to finish (where appropriate). In newer projects members are involved in developing the questions and designing the trials.

It is expected that our members will be heavily involved in translating the results and in assisting in the dissemination of these. In the future there will also be opportunities for our members to be involved in conducting research where some of the groups members may be trained to interview and conduct focus groups in

partnership with professional research staff.

Below illustrates how PPI volunteers are involved within Cardiac & Pulmonary Rehabilitation at UHL.





## Project Updates

Our PPI members are linked to over 13 different projects, in which they are involved in providing helpful and productive advice and support to the professionals.

Here is an overview of a couple of the studies currently ongoing:

The EXPAND study is looking into EXploring patients Perceptions following an Acute exacerbation of Chronic

Obstructive Pulmonary Disease to inform tailored strategies to enhance Pulmonary Rehabilitation.

The SPACE study is a study which promotes 'Self management Programme of Activity Coping and Education'. This study is testing how well a home-based programme of exercise and education works for people with COPD, patients are randomised and some are given a book which

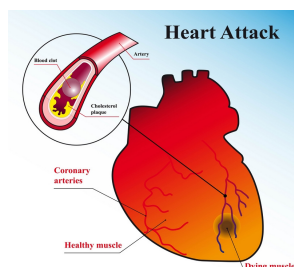
supplies them with all the information about what exercises to do and how to best manage the symptoms of their condition with the ongoing support from the professionals too.

**SPACE**  
FOR COPD

## Different Conditions Explained? FAQ

What is the difference between a Heart Attack & Angina?

A heart attack (also known as a myocardial infarction) means that part of your heart has been damaged by a lack of oxygen. This damage is permanent. The coronary arteries deliver oxygen to the heart muscle (the myocardium). When one or more of the arteries supplying the heart becomes blocked, the oxygen supply to the myocardium stops and the part of the heart muscle supplied by that particular artery dies. This is called a



myocardial infarction.

Angina is a term used to describe the symptoms you have when

the heart muscle is not receiving enough oxygen. This is mainly due to a narrowing of the coronary arteries that reduces the blood flow to the heart muscle. This does not cause permanent damage. The pain is of-

ten described as a heaviness, tightness or pain in the centre of the chest, which may spread to the arms, neck, jaw, between and the shoulder blades. Most angina occurs on exertion and is relieved quickly at rest or by using medication, such as Glyceryl Trinitrate (GTN) spray.

Symptoms that are not relieved within 15 minutes must not be ignored. You must dial 999 as it could be a heart attack not angina.

What is the difference between Asthma & Chronic Asthma?

A: Asthma is a common disease affecting about five million people in the UK. Asthma often starts in childhood, but it can happen for the first time at any age. People with asthma have sensitive airways which become irritated and inflamed in response to triggers such as cold air, perfumes, pollen and dust. The airways become narrow causing shortness of breath, wheezing and coughing. These epi-

sodes may be described as 'asthma attacks.' Patients with asthma generally have inhalers to help control their symptoms. Some treatments are for rapid relief of symptoms (relievers). Others, such as steroid inhalers must be taken regularly, whether or not the patient has symptoms (preventers). With normal



asthma, there is no permanent obstruction within the lungs and inhaled drugs work effec-

tively to open up the airways.

Over time, asthma can start to behave more like COPD. When asthma becomes chronic, there is always some fixed obstruction within the lungs so merely taking reliever inhalers does not reverse the obstruction.

At this stage patients may be told they have chronic asthma or COPD and a diagnosis is made by performing lung function (blowing) tests.

We hope you enjoyed our 1st Edition Newsletter. If you would like to become involved within our Patient & Public group or you would like to receive future copies of this Newsletter, please contact the PPI Editing Team. Thank you.

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In our next edition....

Updates on our current projects.

All the latest news from PPI.

Rehab stories.

And much more...

