

# BEST FOOT FORWARD

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

Volume 1, Issue 2

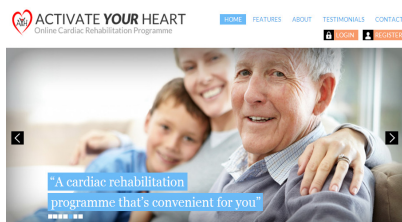
September 2013

Welcome to our second edition of the Cardiac & Pulmonary Rehabilitation Patient and Public Involvement Group Newsletter. Created by members of our PPI group with the aim of updating the community on relevant rehabilitation activities in the Cardiovascular and Pulmonary rehabilitation departments.

## The first online cardiac rehab programme gets nominated for an Award

The first ever online cardiac rehabilitation programme, designed by the Cardiac rehabilitation team in Leicester has been shortlisted for the Nursing Times Award 2013. There were many entries for the cardiovascular services category, so to be shortlisted is a great achievement for all the cardiac rehabilitation team and patients who played a big role in the programme's success. The winner will be announced on 30th October.

The 'Activate Your Heart® (AYH)' programme provides to help those



people who have had a recent cardiac event or have an existing cardiac problem and enables them to manage their condition more effectively. Cardiac rehabilitation is recognised as one of the most effective interventions to help individuals with coronary heart disease achieve a full and active life. 'Activate Your Heart®' offers an effective and alternative approach to cardiac rehabilitation. Providing greater choice to our patients.



Professor Sally Singh, head of cardiac and pulmonary rehabilitation said: "This is a fantastic tool to help patients who have recently suffered with a cardiac event, or have an existing cardiac problem to continue to live active lifestyles. It allows patients to take a lot more control over the rehabilitation process, with the flexibility to suit their lifestyle." PPI member Phil Caldwell, who used the programme following a heart attack nearly two years ago,

described how he benefited from its flexibility. He said: "The nature of my job meant that I was never going to be able to attend regular rehab classes at the hospital, so using the programme allowed me to re-build my exercise and confidence levels in my own time. The programme also contained a wealth of knowledge about my condition, lifestyle and risk. The goal-setting and exercise diary functions were really motivational. Having been through the experience and maintained many of the good habits I learned from the programme, I'm convinced 'Activate Your Heart®' is a real solution for cardiac patients who decide that, for whatever reason, traditional rehab programmes are not for them."



'Activate Your Heart®' team, including our PPI members Phil (front row) and Jonathan (back row 2nd left)

 **AYHLeicester**

**CLAHRC**

Leicestershire, Northamptonshire  
and Rutland (LNR)

**NHS**

National Institute for  
Health Research

# What is Cardiac Rehab?

In the UK, approximately 300,000 people have a heart attack each year. Cardiac Rehabilitation is a cost-effective, evidence based approach to managing heart disease.

Despite this, uptake to cardiac rehab in the UK is only 44%!

## Aims of Cardiac Rehab

- To help you identify your risk factors
- Reduce the risk of further cardiac events and mortality
- Support and motivate you to make lifestyle changes
- Improve your levels of exercise and physical activity
- Improve your Quality of Life and Confidence
- Help you to manage Stress and Anxiety

- Help you to understand your Medication
- Reduce Readmissions

## What to expect

- In hospital visit
- Telephone call after discharge
- Attend Education session
- Comprehensive Individualised assessment with a cardiac rehab specialist
- Individual exercise programme, either in the hospital/community or via the web
- Assessment following completion of programme.



## Common questions

**Q.** I am not able to exercise or walk far.

**A.** Exercise is an important component of cardiac rehab. However there are many other areas which cardiac rehab can address.

**Q.** Am I too old to go to gym classes?

**A.** No. We have all ages in our classes, from 19 to 90!

**Q.** I don't have time to come into hospital for the rehab classes. What else is there?

**A.** The hospital classes may not be appropriate for you. Fortunately the cardiac rehab department have other programmes, which maybe suited to your needs, such as attending classes at a local gym, or even using our online cardiac rehab programme - *Activate Your Heart®*

# National Conference attendance

## INVOLVE Conference Nottingham Conference centre November 12th/ 13th 2012

INVOLVE is a National advisory group which promotes and supports greater public involvement in NHS, public health and social care research, funded by the National Institute for Health Research (NIHR).

Before attending, Chris Brough (PPI lead) and 2 members of the PPI group, Jonathan and Phil designed a poster explaining the principles of the 'Activate Your Heart (AYH)' online cardiac rehabilitation programme. Theresa Harvey-Dunstan (PPI Lead), and PPI members Pat Brickley, Mick Vose and Maddy Alton designed a 2nd poster explaining the role, involvement and progress made by this group. Gemma made 2 eye catching posters which were displayed at the conference, for all the participants to see and discuss our work in the intervals between lectures and presentations. Maddy attended a session where PPI groups had begun to evaluate the impact of their contributions on the structure and content of the research itself, communication with patients and health service professionals (and trainees) and detail of what care was delivered and how it was given, to mental health pa-

tients.

## Questions addressed:

*How do PPI groups the researchers, funders and managers know the extent to which the PPI influences the shaping of research, and implementation of research ideas?*

Keeping a log of all the proposals and suggestions made, by whom at what level and the result of the discussions for each research programme. How outcomes were communicated to relevant parties, and what action was planned as a result, what action taken, what results were recorded, by whom and when. The PPI recommendations were divided into categories of influence including Scientific, pragmatic, resources, working practices and collaborations.

*How to obtain the greatest benefit from PPI members?*

To recruit skilled members of the PPI group early in the development of the research idea, will be useful to the whole process of research and delivery, by using them to help to shape the research direction, methodology, content and perspective.

- In addition researchers are required to understand the role of the PPI group.
- Agree timescales of commitment from PPI members and succession planning.
- Provide support for PPI groups to operate.

*How to be sure the PPI is reflective of the service users in the area of research?*

For each area of research; identify people of a suitably diverse group in age range, ethnicity, gender, and social groups reflecting the service users, with the key skills, availability and capabilities to build a successful group.

These matters were reported back to the following PPI group meeting for discussion and for consideration of adoption.

*Maddy Alton—PPI Deputy leader*



Mick Vose



Sally Boyce & Maddy Alton

## Members Profile: John Hawkes

I retired from an interesting and varied career as a Senior Lecturer in Design Management at Surrey University following an earlier retirement as a Main Board Design Director for a number of leading toy companies, including Palitoy, Bluebird Toys, Matchbox and Airfix, so a retirement from this active Design and Design Management life I felt was well deserved.

It was whilst enjoying this that on October 31 2010 I settled down to enjoy breakfast with my wife, but within an hour, I was in Glenfield Hospital with Doctors and Nurses fighting for my life following a huge heart attack. I arrested five times and was described as very poorly, a term not used without concern for recovery.

A worrying time for all.

After some time in Intensive Care I recovered enough to go home, and I joined the Hospital Rehab programme to help further recovery. This was great fun, with lots of laughs, but at times quite challenging. Meeting other cardiac patients there helped me enormously and medical staff were on hand at each session to discuss any worries I had about my condition. At the end I continued Rehab at a Hospital designated Gym, and then at home. Why do Rehab, well to me it offered the best road to recovery. It took time and determination but I knew I had to do it, because I owed it to my family and all those who had worked so hard to save my life. Had I ignored Rehab I wouldn't be back playing golf regularly, enjoying my

family, and doing all the things I thought I would never do again. Don't ignore Rehab because it builds confidence, improves stamina and fitness, and for me was a life changing experience. I now feel so positive about my recovery, revitalised physically and mentally, and feel I had achieved something special

.....overcoming my fears and getting back to enjoying my life again.

Remember if you have any doubts about Rehab do it because you owe it to yourself and your family to get back to the enjoyment that being with them brings. Now for me every day is a bonus, and thanks to the Glenfield Medical Team and the Rehab staff I am still around to enjoy every moment of it.

*John Hawkes, PPI member*



**John Hawkes**  
Cardiac & Pulmonary Rehab PPI Member

## PPI activity

Since the last newsletter in September 2012, there has been a lot of activity and attendance at various conferences & seminars for the group.

**2 November 2012 - Activate Your Heart®** Website was launched, two PPI members presented at this event, Phil Caldwell & Jonathan Mansfield. Their presentations regarding their experiences with PPI gave a very powerful message.

**13 November 2012 - National INVOLVE Conference.** The team had 3 abstracts accepted at this conference, two posters & one presentation. The PPI members were involved in producing all three abstracts. The verbal presentation given was regarding the impact PPI involvement had had on implementation within the hospital, the team were congratulated on this input, as they were the only ones who had utilised their PPI members skills in this way.

**30 January 2013 - CLAHRC Rehabilitation Theme, Dissemination Event.**

This was a showcase of all research activity produced over the past 4/5 years, including presentation from Jonathan Mansfield on how PPI involvement had contributed to and improved the AYH project, again this was a very strong and powerful account of how PPI can truly help with a project.



*Showcasing our PPI work at the NIHR PPI Research Open Day held at the Brite Centre in Leicester.*

**26 March 2013 - NIHR PPI Research Open Day held at the Brite Centre in Leicester.**

This event provided opportunities for members of the public to get involved in research studies. Chris Brough presented at the

event information regarding our PPI group, there was a lot of public interest resulting in new members wanting to join our PPI group.

**19th June - Making it Real: Patients and public improving healthcare research.** This was an 'Open Space' style event for patients, the public, researchers and healthcare professionals. This was another good opportunity to highlight our research projects and the work our PPI group are doing.

**Partners in Projects: Public Engagement in Research Course.** Our PPI members have been given the opportunity to attend a course to learn more about research. The aim of the course is to fully equip our PPI members with the skills and confidence to approach involvement in service research, development, delivery and evaluation. The course will be held at GGH, over several sessions.



# Volunteers needed

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## Volunteers needed for 3 new exciting studies

### MATCH

#### Mitochondrial adaptations to Aerobic Training in COPD and Health

Study to find out how the muscles of COPD patients adapt during a training programme in comparison to people without lung disease.

The project team are looking for patients with COPD and healthy people who would like to take part in this trial. If you are interested, and fulfil the following criteria, please get back to us.

#### Inclusion Criteria COPD patients

- Diagnosis of COPD
- Age 60-80 years
- Ex-smoker (>1 year)

#### We also need healthy participants

- Ages 18-30 and 60-80 years
- Ex-smoker (>1 year ago) or non-smoker

#### Exclusion Criteria

- Diabetes Mellitus
- On Long Term Oxygen Therapy
- On Warfarin
- On long-term steroids

#### What does it involve?

- One-to-one supervised exercise bike training for 8 weeks
- Small muscle biopsies in quadriceps involved over 12 weeks

- 5 planned visits at the QMC in Nottingham.
- Parking/travel costs paid for
- Small inconvenience fee of £150 paid at end of study.

If you require more information about this project let us know.

### COPD Web Study

#### A feasibility study to evaluate an interactive web based Pulmonary Rehabilitation programme

#### Inclusion criteria:

- Willing to undertake pulmonary rehabilitation
- Willing to take part in the web-based pulmonary rehabilitation programme if randomised to that arm of the study
- Access to the internet and ability to navigate around a variety of websites (for example, uses online shopping or banking websites) or regular use of email
- An established diagnosis of Chronic Obstructive Pulmonary Disease (COPD)
- Medical Research Council (MRC) dyspnoea score of between 2 and 5

### EXoS

#### A comprehensive comparison of the sensitivity of common Exercise outcome measures for Chronic Obstructive Pulmonary Disease (COPD)

#### Inclusion Criteria

- COPD and moderate to severe airflow obstruction
- Breathless on walking
- Age 40-85 years
- Exclusion criteria
- Co-morbidities that limit the ability to walk/cycle, for example musculo-skeletal, arthritic, or neurological disorders.
- Participation in pulmonary rehabilitation over the last 12 months
- Participants on LTOT therapy and those require oxygen therapy during the course of an exercise test (i.e. desaturation documented below 85%)



If you would like to know more about our current studies or become involved.

Please contact Gemma McCarthy:  
gemma.mccarthy@uhl-tr.nhs.uk

## FAQs - What is PCI?

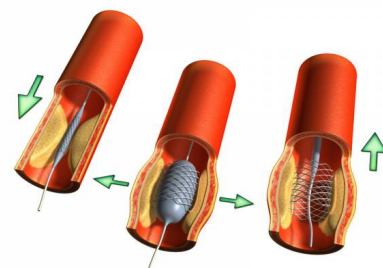
**Percutaneous Coronary Intervention (PCI)**, also called coronary angioplasty and stenting, is a specialised treatment to stretch the coronary artery and so reduce or unblock narrowed arteries.

This procedure involves inserting a fine plastic tube (referred to as a sheath) into an artery through a small puncture hole in the groin (preferably) or wrist. The sheath is very narrow – approximately 3mm wide. A fine tube called a guide catheter is threaded up through the sheath to the

heart and positioned at the beginning of the coronary artery. A fine 'balloon catheter' is then threaded through the guide catheter into the narrowed part of the artery. The stent – a thin metal frame or tube – is mounted on the balloon catheter. Once the balloon catheter is in place, it is inflated. This causes the stent to expand and be pressed up against the wall of the artery.

The balloon is then deflated and removed, leaving the stent in place to keep the ar-

tery open. More than one stent may be needed to gradually widen the narrowing and achieve a satisfactory result.



## Contact us

If you would like to know more or become involved within our Patient & Public group, please contact the PPI Editing Team.  
Phone: 0116 258 3652 or E-mail: gemma.mccarthy@uhl-tr.nhs.uk