



# Patients Matter

Reg. Charity No 292157

N.A.P.P. Quarterly Newsletter

Online Version – Autumn/Winter 2012

## PPG Awareness Week and N.A.P.P Annual Conference 2013

**Saturday June 8<sup>th</sup> 2013** is the date for the next N.A.P.P conference. The theme is **Primary Care in the digital age – What does this mean for patients, quality and continuity of care** will be held at the MShed, overlooking the floating harbour in Bristol. More details will follow shortly on our website and in the e-bulletin.

We are also pleased to announce the first national **PPG Awareness Week** which will be held in the week prior to the conference, from **3<sup>rd</sup> to 8<sup>th</sup> June 2013**.

This is in response to a call from our PPG members at last year's conference for a national campaign to promote Patient Participation Groups and their contribution to primary care. The Awareness Week will be an annual event held during the week prior to the conference. We are busy developing a national media campaign around the 'week' and will release more details of this very soon also how your groups can get involved. Please send any ideas you may have to ensure we maximise this opportunity to:-

[stephanie@varah.plus.com](mailto:stephanie@varah.plus.com)

## In this Issue

	Pages
<b>PPG Awareness Week</b>	<b>1</b>
<b>Mission Impossible</b>	<b>2</b>
<b>N.A.P.P. Needs You!</b>	<b>2</b>
<b>Doctors Revalidation</b>	<b>3</b>
<b>Helping to Improve the NHS</b>	<b>4-5</b>
<b>You could improve the Quality of Health Research</b>	<b>5-6</b>
<b>Getting ready for GP registration:</b>	<b>6</b>
<b>PPG Newsletters</b>	<b>6-7</b>
<b>Summary Care Records</b>	<b>7</b>
<b>Messages from the Editor</b>	<b>7-8</b>
<b>N.A.P.P. Executive and Trustee Contact details</b>	<b>8</b>

## Mission Impossible... Self-care for life – Growing older healthily

As the national patient's champion for the Self Care Forum, N.A.P.P played a leading role in the Annual Self Care Conference held in central London on 8<sup>th</sup> November 2012. The aim of the conference was to stimulate debate on whether it is an impossible task to change how the NHS and health professionals promote self-care; and whether patients have sufficient confidence to make the change towards self-care, whether it is to manage their everyday health problems like coughs and colds, or to care for long-term health conditions as we age. PPG representatives joined with other expert speakers to share their views on what needs to change to make self-care happen.

Many PPGs already promote good health to their local communities. Almost forty PPG members have now signed up as N.A.P.P 'self-care champions' and are becoming more actively involved in the self-care campaign.

Supporting self-care provides a further opportunity for PPG members to have an active role in their GP practice; ensure that local people understand and get the best out of their NHS services; and that local GPs, nurses and practice staff are able to focus on providing treatment and support for those with long-term and complicated health problems.

The campaign also offers an opportunity for PPGs to raise their profile, and further develop their role as advocates for the

NHS and its services in their community.

N.A.P.P has developed a Self-Care Guide for PPGs which will be circulated to member groups in the coming months. To learn more about the self-care campaign or sign up as a PPG champion please contact Stephanie at [stephanie@varah.plus.com](mailto:stephanie@varah.plus.com) or visit [www.selfcareforum.org](http://www.selfcareforum.org)

## N.A.P.P needs you!...

Momentum is growing apace and there is so much happening in the world of PPGs that it's difficult keeping up sometimes...The N.A.P.P membership has doubled in the last six months and we have Clinical Commissioning Groups also joining along with their member practices and groups. The N.A.P.P community now represents over ten million patients and increases daily!

We need your help to be our eyes and ears on the ground and to help us ensure our support is getting to the places it needs to reach. We are looking to establish some '**regional representative**' roles so that we can have a greater local presence. At this stage the roles will be voluntary but we are actively seeking appropriate funding to pay reasonable expenses.

If you are interested in helping to drive forward this progressive movement in these exciting times and would like to know more please contact Stephanie at [Stephanie@varah.plus.com](mailto:Stephanie@varah.plus.com)

## How you can help doctors give you the best care

At the General Medical Council our job is to protect patients and help to improve the standard of practice provided by the UK's 230,000 licensed doctors.

From December 2012, we are introducing a new system of checks for doctors. This new system is called revalidation – and we need help from patients to make it work.

The principle behind revalidation is that every doctor should have an annual appraisal, when they will be expected to reflect on their practice and consider what they have been doing well and the areas where they could improve. Every doctor will have to collect a range of information about their practice, including complaints, compliments and concerns from patients. In addition, at least once every five years doctors have to collect formal patient feedback. That means doctors must ask a random set of patients who have consulted them, what they think about the doctor's performance.

In many areas these surveys are already used, but this is the first time that they will be compulsory for every doctor. If you are asked to, please do take part in one of these surveys – the feedback you give will help the doctor develop their skills and identify how they could care for you more effectively. The surveys will be anonymous so the doctor will not know who has commented.

It must be stressed that this is not a new way to complain or raise a concern about the care you have received. If you do have a problem about any aspect of your care and

treatment, you should complain in the normal way – ask the doctor, their colleagues or practice managers in general practice, for information about how to do this, as it varies in different organisations. Usually a doctor will only be able to act on your complaint, and be accountable to you, if they know who you are.

While the formal feedback from patients will be collected at least once every five years, we are also requiring doctors to bring every complaint and compliment they receive from patients to their annual appraisal. We expect all doctors to reflect on these and to show what they have learnt from them.

Revalidation is the biggest change in medical regulation for more than 150 years. We will be the first country in the world to put in place such a comprehensive system of checks, and it will take time to get it just right. But for now, it is a major step forward in making sure we all receive the best care our doctors can give.

*We are very grateful to Niall Dickson, Chief Executive and Registrar of the General Medical Council, for drafting this article.*

**We urge all our affiliated PPGs to send us articles/photographs etc. for inclusion in the quarterly N.A.P.P. Newsletter. Your contributions matter as they can assist other PPGs (particularly newly formed groups) in their activities. Sharing information is one of the keystones of our Association.**

**Please send your material to the Editor [danny.daniels@napp.org.uk](mailto:danny.daniels@napp.org.uk)**

## Helping to improve the NHS

**We are grateful to Tracey Johns, PCRN (Patient & Public Involvement Manager NIHR Primary Care Research Network) who provided this article**

Healthcare research plays a key role in helping the NHS to understand, adapt and respond to the challenges it faces - without it, medicine cannot progress and healthcare will not improve.



What many people don't realise is that this research is not limited to the big teaching hospitals; it's happening in all parts of the NHS and that includes your local GP surgery. Last year alone over 200,000 patients took part in research supported by primary care practices and practitioners.

Professor Paul Wallace, director of the Primary Care Research Network, explains why this research is so important:

*“Around 90 per cent of NHS patient contacts take place in primary care, so it's critically important to have a strong evidence base to inform practice in this area and ensure that the treatment and healthcare decisions that health professionals make are based on the most up-to-date medical information and evidence. There is also growing evidence to suggest that patients that are cared for in research-active NHS organisations have better health outcomes than those looked after by services that don't do research.”*

### **So what does this research involve?**

First of all, it's not just about testing new drugs. It's true that some research may involve taking a new medicine - sometimes a breakthrough or life-saving drug treatment before it is generally available on the NHS. However, a lot of research involves using existing medicines in new ways, or in new combinations, to see if we can make them more effective. Other studies are observational; they may simply ask the patient to provide details about their lifestyle, and how it is affected by their condition, and don't involve taking any medicines at all. Whereas some research studies use other interventions, for example text message support, patient support, exercise or education programmes.

Secondly, participation in research is purely voluntary. In a recent national poll, 82% of the public thought it was important for the NHS to offer opportunities to take part in clinical research, and fewer than 7% said they would never take part. Patient participants have the opportunity to discuss the research and ask as many questions as they like before agreeing to take part, are kept fully informed throughout the research project, and can decide to drop out at any time.

## **And why do patients volunteer to take part?**

The key word here is “volunteer”, and NHS patients volunteer to take part in research for a variety of reasons, for example:

- It may offer an alternative or new treatment option
- Because they want to help other people like themselves in the future
- For personal reasons; because they want to learn more about their disease or medical condition and how they can overcome it/learn to live with it.

Brian Ruel is a patient at the The Surgery in Honiton, Devon. He describes how and why he became involved in research:

*“I was first approached by my GP who is very research-active. In my younger days I was a sportsman which has left me with a number of painful injuries and means that I have taken strong opiate-based pain relief for a number of years. When the opportunity arose, my doctor suggested that I might benefit from taking part in a pain management study. I didn’t hesitate. I trusted my GP when he said it might help me and I was keen to contribute because helping these professionals build their knowledge will help other people like me in the future.*”

*“I certainly gained a better understanding of my own situation and of others like me. I also think it stopped me from becoming withdrawn. I have mobility problems and as a result I don’t socialize much and have a tendency to become depressed. But I got a great sense of personal satisfaction and really valued the time I spent helping medical professionals.*”

*“It’s snowballed from there; I’ve become actively involved in research in a number of ways since, mainly looking at patient experiences. Through this work I’ve found that most patients want to have the opportunity to find out more about their own conditions for their own benefit, and they’re also keen to help find answers to questions to help other people with similar conditions.*”

*“I think it’s important that our body of knowledge keeps pace with the growing demands on our health service. We have a growing and ageing population with a whole spectrum of medical problems. It’s essential that we do more research to make sure that we are better equipped for the future.”*

## **So how do patients get involved?**

Across England, the Primary Care Research Network ([www.pcrn.org.uk](http://www.pcrn.org.uk)) is working with local Practice Participation Groups PPGs. Members of some PPGs are involved with the Network as patient representatives on local research groups and some Network staff regularly attend PPG meetings to share information about local research opportunities and results. Alternatively you can ask your health professional about taking part in research that is suitable to you, or look online at the UK’s Clinical Trial Gateway ([www.ukctg.nihr.ac.uk](http://www.ukctg.nihr.ac.uk)) to find out what research is happening in your area.

You can also contact the Primary Care Research Network directly:

Tracey Johns, [tracey.johns@nihr.ac.uk](mailto:tracey.johns@nihr.ac.uk) ,  
Tel: 0203 328 6742

## **YOU could improve the quality of health research**

***Following on from the previous article this call (also for patient volunteers) was received from The National Institute for Health Research***

The National Institute for Health Research (NIHR) funds research for the NHS into a wide range of health conditions, treatments and services. It's important that patients, carers and members of the public with relevant experience are involved in research, to ensure that the patient perspective is taken into account.

If you have personal or family experience of a health condition or use health or social care services, we would welcome your involvement in the work of our funding programmes.

All research briefing papers and research proposals for Department of Health funding need a patient/public reviewer. You may be just the person we are looking for. These are occasional tasks that are done at home at your own pace, with guidance from us. We pay a small fee for all review work to acknowledge your important contribution. You don't need to have worked in research or to have any particular qualifications. By looking at these documents and advising us from the patient point of view, you can help improve the quality of our publicly-funded research.

From time to time other opportunities come up such as membership of commissioning boards or committees. People with experience of doing reviews for us sometimes apply for these.

To find out more, see our web pages [http://www.netscc.ac.uk/getting\\_involved/](http://www.netscc.ac.uk/getting_involved/) email us at [netsppi@southampton.ac.uk](mailto:netsppi@southampton.ac.uk) or call 023 8059 9302.

## **Getting ready for GP registration: Care Quality Commission and N.A.P.P working together Next steps...**

In April 2013 the Care Quality Commission (CQC) will begin monitoring GP practices. CQC recognise it is very important that they listen to the views and experiences of people who use services and in particular that they involve representative groups in their work. In May and June 2012 CQC and NAPP ran three workshops to look at how best to work with PPGs in the future and to identify what they would need to do to prepare for this. CQC also worked with some PPGs in a series of pilot inspections during the summer

The full report from the pilot exercise, setting out their approach to monitoring primary medical services, is on both the CQC and N.A.P.P. websites.

N.A.P.P and CQC will continue to work together to develop a stronger relationship between CQC and PPGs including helping PPGs to understand the national standards and the compliance monitoring process. This will be done through a combination of articles and information disseminated via the N.A.P.P website, e-bulletins and Newsletters, development of a guide for PPGs and briefings. A small group of PPG members has been established from those representatives who attended the earlier workshops. These individuals are undertaking a piece of project work with CQC to deliver a set of resources and information for PPGs.

## PPG Newsletters on our Website

We thank the PPGs who are regularly forwarding copies of their newsletters to Edith Todd at [edith.todd@napp.org.uk](mailto:edith.todd@napp.org.uk) for display on our website. However we would encourage more subscribers to participate. We do not know how many PPGs produce such newsletters on a frequent basis but with our increase in numbers of affiliates there must be a wealth of valuable information and examples of good practice lying dormant to the wider world of Patient Participation.

Why not navigate to the PPG Newsletter page and browse through some of the articles and links contained therein. There are many examples of excellent practice by our subscribers which could be beneficial to other affiliates.

We look forward to receiving other contributions.

## What's happening with the Summary Care Record in your area?

As the NHS changes, the importance of keeping patients at the centre of their care is essential. With almost 22 million patients now having a Summary Care Record (SCR), amounting to almost 40% of the country, how can the SCR work for you?

An SCR is an electronic record which contains information about the medicines you take, allergies you suffer from and any bad reactions to medicines you have had.

Having access to this essential information makes it easier for healthcare staff to treat you in an emergency, or when your GP practice is closed. To learn more about the benefits of the SCR visit: <http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/comm/s/case>

3,000 GP practices across the country have now created SCRs for their patients. Find out if your own practice is one of them by visiting our deployment map: <http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/impguidpm/deploy/>, or alternatively ask your practice if they have created SCRs or when they plan to do so.

**Want to know more?** In addition to checking out the SCR web pages you can also:

Follow the SCR programme on Twitter: <https://twitter.com/NHSSCR>

Sign up for the regular SCR email bulletin:

<http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/bulletin/maillist>

The record that is being introduced in Wales does not form part of the English electronic summary care health record. In Wales, there is a different approach.

## Diary dates

**Annual Conference: 8<sup>th</sup> June 2013**

**PPG Awareness Week: 3rd –8<sup>th</sup> June**

**Corkill Award: 31<sup>st</sup> March 2013**

## Messages from the Editor

Sincere apologies for the late publication of this Newsletter issue. Technical problems were the major contributor to this situation.

Looking forward to this New Year, we have three major events happening in the week commencing Monday 3<sup>rd</sup> June

- The Patient Participation Group Awareness Week.
- The Corkill Award winner for 2013
- The Annual N.A.P.P. Conference and AGM

To elaborate on the PPG Awareness Week; we would welcome any ideas or suggestions etc. on what we could do

- a. on a national level and
- b. to help individual PPGs

The Corkill Award entry forms and associated criteria are being finalised and should be ready for distribution on request by January 25<sup>th</sup>.

We hope to finalise details regarding the Annual Conference in February.

We are in receipt of a copy of the Seaton Park Patient Group's first Newsletter. A thank you to Len Humphries the group's Chair for this informative and patient focused publication.

And finally we wish all our affiliated groups and contributors from the many diverse organisations who have sent us material for publication a Happy New Year.

## Board Members contact details

**Dr Patricia Wilkie**  
President & Chair  
e-mail [pwilkie@inqa.com](mailto:pwilkie@inqa.com)

**Stephanie Varah Chief Executive**  
e-mail: [stephanie@varah.plus.com](mailto:stephanie@varah.plus.com)

**Edith Todd – Treasurer & Membership Secretary**  
e-mail [edith.todd@napp.org.uk](mailto:edith.todd@napp.org.uk) .  
Tel: 01932 242350

**Danny Daniels – Vice Chair**  
e-mail: [danny.daniels@napp.org.uk](mailto:danny.daniels@napp.org.uk)  
Tel: 02920 511016

**Sylvia Debreczeny – Trustee**  
0208 386 4247  
e-mail: [sylvia@sylviadeb.demon.co.uk](mailto:sylvia@sylviadeb.demon.co.uk)

**Dr John Dracass – Trustee**  
e-mail: [dracsj@aol.com](mailto:dracsj@aol.com)

**Sandy Gower – Trustee**  
e-mail [S.Gower@nhs.net](mailto:S.Gower@nhs.net)

**Sue Line - Trustee**  
0247 6313823  
e-mail: [sue.line@btinternet.com](mailto:sue.line@btinternet.com)

**Dr Roger Till – Trustee**  
0207 249 2504  
e-mail: [roger.till@debeauvoir.co.uk](mailto:roger.till@debeauvoir.co.uk)

**Margaret Matthews – Trustee**  
email: [maggiermatthews@tiscali.co.uk](mailto:maggiermatthews@tiscali.co.uk)

**John England – Trustee**  
e-mail: [john.england@btinternet.com](mailto:john.england@btinternet.com)



**N.A.P.P. Corporate Member**

The logo for Emis consists of the word 'emis' in a bold, lowercase, blue sans-serif font. A registered trademark symbol (®) is located to the upper right of the 's'.

**Official partner of N.A.P.P.**