



# Patients Matter

Charity No 292157

N.A.P.P. Quarterly Online Newsletter.

Autumn/Winter 2010

## Message from the Editor

Welcome to this our first dedicated online issue of the Newsletter. We have decided to publish on the N.A.P.P. website prior to circulation of the hard copy. The amount of information that is now available, which we would like to share with our affiliates, is rapidly rising. Change appears to be accelerating rather than flattening out.

The monthly e-bulletin is useful and appreciated by affiliates but does not allow any depth. We would appreciate your feedback on matters relating to the provision of electronic communication.

You will obviously notice the change of logo which is compatible with the PPG stickers offered to PPGs earlier this year. The title of the newsletter has also altered to reflect N.A.P.P.s beliefs.

A final plea: Please forward your comments & articles for inclusion in the newsletter to me via email at [danny.daniels@napp.org.uk](mailto:danny.daniels@napp.org.uk). Thank you

Danny Daniels N.A.P.P. Newsletter Editor

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official partner of N.A.P.P.

**N.A.P.P. New Appointments** N.A.P.P. welcomes to the Executive Board the following appointees. We have been seeking to strengthen the board for some time. We believe that these appointments will enable us to further the concept of Patient Participation within the UK. At the same time we aim to foster the valuable contributions which active PPGs are frequently demonstrating. We have a policy and strategy meeting of the board scheduled for early in the New Year. If you have any comments on our performance or ideas associated with additional benefits we can deliver please let us know. We shall consider all offerings and wherever possible and feasible undertake to implement them. Please send your contributions to our Administrative Secretary Edith Todd, ideally electronically, at [edith.todd@napp.org.uk](mailto:edith.todd@napp.org.uk) . If this is not possible please write to: Mrs Edith Todd, 19 Harvey Road, Walton on Thames, Surrey, KT12 2PZ. *(It would be helpful if we can receive your ideas by 28<sup>th</sup> January 2011)*

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**Stephanie Varah: N.A.P.P. Director for National Development  
Independent Consultant**

**Director – Stephanie Varah Development Solutions Ltd**

Stephanie has over 25 years' experience of working at the leading edge of public and patient involvement in health, social care and the voluntary sector. She was involved in the late 1990's in laying the foundations of the modern NHS Patient and Public Engagement and Empowerment framework.

In 2001, Stephanie was shortlisted as a national finalist for a Cabinet Office Modernising Government Partnership Award for developing and implementing a user involvement organisational change programme for a large social services authority.

As Patient and Public Engagement/Patient Experience (PPE) Lead for Trent Strategic Health Authority and NHS East Midlands Stephanie pioneered the involvement of patients in SHA performance management reviews and led a national project for the Department of Health to develop performance indicators and evidence measures for PPE and Patient Experience.

In December 2006 Stephanie became a full time independent consultant and was commissioned by the Department of Health in January 2007 as project manager for the LINK's Early Adopter Programme and subsequently as national co-ordinator for the LINK's implementation programme until December 2008.

Stephanie has continued to support the Department of Health on a number of national LINKs projects in the last three years and has also been commissioned by the Department for Communities and Local Government to support four LINKs participating in a two year national government pilot testing the potential of LINKs as a mechanism to collect feedback on all public services.

She is now supporting a Care Quality Commission project to develop a productive relationship with LINKs and has recently been appointed as the Director for National Development for the National Association for Patient Participation. During initial consultations Stephanie said to the Board:- *"I can clearly see the unique role & benefits of PPGs & how they can work alongside with & complementary to LINKs so my intention is to promote PPGs & fight for their individuality in the new system."*

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## **Royce Franklin**

### **Chair of the National Association for Patient Participation**

Royce served over 50 years in the criminal justice system, predominately as a probation middle manager but initially as a Police Officer. He has vast experience in multi-agency work particularly through his work with homeless offenders and in Manchester prison. In the early 1980s he graduated from Cranfield College of Technology with an MSc after writing a thesis on the homeless offender in a large city. There, he has been Vic-Chair throughout its existence and been the editor of the newsletter. He has been a Q.O.F. lay representative for Oldham P.C.T. for the past 5 years. He became a N.A.P.P. trustee in 2008. He is a Parish Councillor and chairs the local Homewatch group. He is a keen supporter of Oldham Athletic Football Club and sings in a local choir. Royce says: 'I am pleased to become chair of N.A.P.P. at what is probably an unprecedented time of challenge. I am conscious funding is going to be tight but it is hoped we can become more central in commissioning services. This should then attract sufficient funding. Without the dedicated work of my predecessor Danny Daniels and the extraordinary progress N.A.P.P. made under the tutelage of Graham Box and Audrey Hoggard, there would have been no chance whatsoever of N.A.P.P.s involvement at a more strategic level nationally. We have been fortunate to appoint a very experienced Director in Stephanie Varah in place of Graham Box. With her help and guidance and that of the Trustees, I hope N.A.P.P. can continue to progress.

e-mail [royce.franklin1@btinternet.com](mailto:royce.franklin1@btinternet.com) tel. 01457 873416



## **Sylvia Debreczeny**

### **Trustee**

Sylvia initially trained as a nurse and nurse tutor, teaching both pre and post registration courses in London. In 1994 she moved into university teaching, lecturing in health education and NHS management. At the same time Sylvia worked as an independent education consultant, undertaking research and providing commissioned courses for nurses and doctors. In 1997 Sylvia moved into promoting education for primary care teams and became GP tutor in Tower Hamlets under the auspices the London Deanery. This work involved organising education sessions for GPs under the protected learning time scheme and liaising with the PCT in developing their education agenda. In addition, she continued to teach in university and was appointed module leader, contributing to the BA Health Service Management.

In 2002 Sylvia was appointed as Associate Director in the Department of General Practice at London Deanery, the remit for which covered tutor management and support, CPD and appraisal for GPs working towards improving the quality of patient care. This work also involved liaising with PCT education leads across London to promote appraiser development and protected learning time initiatives. More recently, Sylvia was appointed as a member of the GP school board at

London Deanery and since retirement in June 2010 has maintained her interest in promoting quality care by GPs for patients through both the school board and education groups. She hopes to use her experience and interest to further the aims of N.A.P.P. in promoting the development of patient participation groups in future. Email. [Sylvia@sylviadeb.demon.co.uk](mailto:Sylvia@sylviadeb.demon.co.uk)



## **Dr Roger Till**

### **Trustee**

Roger has worked both as a staff director and previously as a non-executive Council member and Chairman, of a membership based, not-for-profit organisation that develops supply chain standards and best practice, including applications for healthcare supply chains (see <http://www.gs1uk.org/what-we-do/sector-solutions/Pages/default.aspx>).

Prior to that Roger was in the private sector, with BP, where he managed the development of exploration mapping applications and the running of computer systems of all sizes. He was also part of a small Head Office team that set global ICT strategy for the BP Group and developed e-Business guidelines. Roger started his professional career as a Lecturer in Geology at the University of Reading where he taught and researched about sedimentary environments and the application of computing and statistics to earth sciences. He now has a number of voluntary roles related to healthcare work and very much looking forward to contributing to N.A.P.P. at this critical time in the development of the NHS and the role of PPGs. The Lawson Practice is based on the edge of Hackney and Roger chairs the PPG and produces the Quarterly Newsletter. He is a patient/carer representative on the NICE (National Institute for Health and Clinical Excellence) Guideline Development Group for 'Managing Stable Angina'. The Guidelines are just going out to public consultation. Roger has been a keen photographer since he was young, especially in b&w, enjoying all the darkroom work and the artistic opportunities of the medium. He is a member of the London Independent Photographers (LIP) and has a number of photography projects in progress. Email [roger.till@debeauvoir.co.uk](mailto:roger.till@debeauvoir.co.uk)

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## **Response to the White Paper**

**N.A.P.P. has been busy compiling a comprehensive response to the White Paper and accompanying Consultation Papers about Commissioning and Local Democratic Legitimacy. N.A.P.P. would like to thank all the PPGs who took the time and effort to submit to our request for input. The responses can now be downloaded from our website: [www.napp.org.uk](http://www.napp.org.uk)**

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## **Launch of inaugural PPG in West Midlands Dental Surgery**

**Royce Franklin, N.A.P.P.'s Chair attended the launch of the inaugural dentists' PPGs in Bromsgrove, West Midland on the 4<sup>th</sup> October. The meeting was convened by NHS West Midlands and led by Patricia Barnett, Programme Consultant, Primary Care and Practice Based Commissioning (PBC). 16 practices attended and there is hope they will become the first practices in dentistry to have a PPG.**

## Department of Health GP Consortia Pilot Programme

N.A.P.P. is pleased to announce that we have been invited to input into the Department of Health's GP Consortia pilot programme looking at how patients and the public can be engaged in commissioning. The programme will amongst other things test how relationships between Local HealthWatch, GP Consortia & PPGs will work in practice. This is an exciting development and we will keep you updated on its progress.

NAPP is keen to receive feedback from individual PPGs involved in any aspect of commissioning at both Practice and Consortia level so that we can build a database of contacts & information to feed into this & other important national activity. Please contact.....Stephanie Varah at [stephanie@varah.plus.com](mailto:stephanie@varah.plus.com)

Local Involvement Networks (LINKs) will become Local HealthWatch (LHW), with their transitional period starting in 2011. Many of the LINK functions will remain the same but there may be additional duties such as providing support to patients around choice and advocacy services. Many PPGs and NAPP trustees have recently attended workshops around the country on establishing HealthWatch. A number of key concerns /issues were discussed, including:

- to be truly independent LHW should not be accountable to the Local Authority
- lack of capacity and skills to provide advocacy services
- training and resource concerns for members/participants
- independence of HealthWatch England (the national body) sitting within the Care Quality Commission)
- PPGs should have a place on the GP consortia
- PPGs need to work closely with LHW

## GP Practices Choices Update

Earlier this year the Department of Health held a consultation on whether patients should be able to register with the GP practice of their choice, regardless of where they live. Responses to these plans to scrap GP boundaries were backed by an overwhelming majority of patients. The consultation identified a number of related issues that will now need to be worked through and discussed with the NHS and GPs. The government will provide a formal response setting out the changes necessary to secure the care and services wanted by the vast majority of the thousands of respondents. The government proposes to give people the ability to register with any GP practice from April 2012.

## New Consultations on the White Paper: An Information Revolution and Greater Choice & Control

An Information Revolution is one of a series of documents for consultation published subsequent to the White Paper Equity and Excellence: Liberating the NHS. It is part of the Government's agenda to create a revolution for patients - "putting patients first" – giving people more information and control and greater choice about their care. The information revolution is about transforming the way information is accessed, collected, analysed and used by the NHS and adult social care services so that people are at the heart of health and adult social care services. To have your say

see <http://tiny.cc/ifezv>

Greater Choice & Control offers proposals for offering more choice for patients and service users:

- How shared decision making can
- become the norm (***continued p6***)

**(continued from p5)**

- How it can happen: information, 'any willing provider' and other tools
- Making safe and sustainable choices

NAPP will shortly be circulating a summary of the key points from these papers to PPGs to help and encourage their feedback on the proposals which NAPP will collate & compile on behalf of PPGs for submission to the government.

## News from Scotland



### What is the Scottish Health Council?

The Scottish Health Council was established in 2005 to ensure that the views of patients, carers and the public are properly taken into account by the NHS. Its role is to improve how the NHS in Scotland involves people in decisions about health services. In addition to a national office in Glasgow, we have a local office in each NHS Board area.

scottish  
health  
council

making sure  
your voice counts

### What does the Scottish Health Council do?

The Scottish Health Council helps to make sure people have a say in the NHS by supporting the NHS in Scotland to share good practice,

exchange ideas and develop new approaches on how to involve people in shaping local health services and involve them as equal partners in decisions about their own treatment and care. This includes working with Primary Care teams to help them develop Patient Participation Groups and to work more closely with established structures such as Public Partnership Forums (PPFs). These forums are networks of local people with an interest in improving NHS services in Scotland. We recently produced a leaflet about PPFs – what they are, what they do, and why people may want to get involved in one.

This leaflet '*Public Partnership Forums: Involving local people in developing local health services*' is available from our website.

### Evolving Practice ([www.evolvingpractice.org](http://www.evolvingpractice.org))

is the Scottish Health Council's website for recording and sharing case studies which demonstrate the participation of patients, carers and communities in shaping and influencing local health services. A number of these case studies are about participation in Primary Care.

### Participation Toolkit

We recently published a Participation Toolkit containing guidance on a range of approaches to involving patients and the public. We will add to this resource to include new and innovative approaches and cross reference them with the case studies in Evolving Practice so that people can see examples of the different approaches in action.

Copies of the above documents and information about the Scottish Health Council can be found at [www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org)

**Are you a member of a Patient Participation group in Scotland?**

**If so we would like to hear from you. Let us know how long your group has been running – what have been your achievements to date and anything that you feel may be of interest to other groups in the UK.**

**Please contact the Newsletter Editor Danny Daniels at [danny.daniels@napp.org.uk](mailto:danny.daniels@napp.org.uk)**

## News from Wales



### FROM:

#### **Sketty and Killay Medical Centres` Patient Forum Chair - Danna Evans**

The first meeting of the Sketty and Killay Medical Centres` Patient Forum was held on 15th January 1997; it was set up "as a group to assist the GPs in expressing the views of the patients". It meets monthly (bar August) in the afternoon on the second Tuesday of the month in Sketty surgery which is in the west of Swansea and is the only one in the area. Both Sketty and Killay surgeries are modern and purpose built to provide a range of medical services for its 21,000+ patients.

The membership of the Patient Forum is restricted to 12 representative patients. The Practice manager and a doctor usually attend the meetings. In the very early days it was decided that the Patient Forum was not to be used to deal with individual patient matters but would deal with general subjects.

Over the years the forum has been active in helping the GPs fight to retain in-house medical services and until recently it held annual public meetings for the patients to come and air their views. Speakers are invited to attend when appropriate, usually when a service is under threat; the members

of the patient forum are well placed to give voice to the concerns of the patients.

The responsibility for the NHS in Wales has been devolved to the Welsh Assembly Government which has resulted in the NHS in Wales being organised and managed differently from those in England, Scotland and Ireland. There are seven area Health Boards and seven Community Health Councils (they report to the Health Boards) which cover the population of Wales. Most recently much of the activity and energies of the Patient Forum have been concerned with the proposal by the Abertawe Bro Morgannwg Health Board to relocate the GP-led `out of hours` service from one hospital in central Swansea to another in the north of Swansea. The service provided by the Swansea out of hours service has been outstanding and is considered by many to be an exemplar. Members of the Patient Forum have attended public meetings and put our case to both the Health Board and the Community Health Council. We have strongly advocated that a 24hr unscheduled care service should be retained at the centrally placed and easily accessible Singleton Hospital.

As a result of this recent activity the Chief Executive of the Health Board and the Swansea locality director met with us at a special meeting on the 24th November 2010 to discuss this and other areas of concern directly with them in a more relaxed environment. The Chief Executive of the ABM Community Health Council has agreed to attend our December meeting.

As you see, the Patient Forum is a responsive as well as proactive group of people - we like to think we rise to the challenges!

## Health News in Brief

### Self-care

If you're living with a long-term condition, you can now access a new tool to help you find out if you are receiving the right care and support:

<http://tiny.cc/0irst>

### 50 lives a day lost to Bowel Cancer

Bowel cancer affects over 38,500 people every year – men and women of all ages – and claims almost 50 lives every day. But if bowel cancer is caught early and treated successfully, it is completely curable. Don't delay! If you have been invited to take part in bowel cancer screening, make sure you do it. It could save your life.

About one in 20 people in the UK develop bowel cancer during their lifetime and over 16,000 people die from it each year. Regular bowel screening using a self-test kit considerably reduces the risk of bowel cancer.

Bowel screening is done via a self-test kit which is sent to your home every two years with full instructions. If you have any questions or would like more information, call Freephone 0800 707 6060.

Further information about bowel cancer can be found at [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)

### TB on the rise

The Health Protection Agency (HPA) has announced a resurgence of Tuberculosis in Britain. Those most at risk include people with family associations to countries with high levels of TB and people whose immunity to infection has been impaired, if left untreated TB can prove fatal. TB is spread through the air when people who have the disease cough, sneeze, or spit. Symptoms of TB include fever and night sweats, a persistent cough, weight loss and blood in the phlegm. Cases of TB occur more often in London followed by the West Midlands. Awareness of TB and early detection are vital to stop its spread.

[www.tbalert.org](http://www.tbalert.org)

## N.A.P.P.

Dr Patricia Wilkie - President

### N.A.P.P. Board

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### N.A.P.P. Executive

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