



Patients Matter

Charity No. 292157

N.A.P.P. Quarterly Newsletter.

Spring 2011

Raising the profile of PPGs in Parliament.

Stephanie Varah was invited recently to give oral evidence on behalf of NAPP and PPGs to an **All Party Parliamentary Group** (APPG) on Primary Care and Public Health Special Inquiry into the coalition government's Public Health White Paper "Healthy Lives, Healthy People".

The NAPP written submission to the APPG can be read on our website www.napp.org.uk

Since giving this evidence the APPG has produced their findings and one of the most important recommendations in terms of the recognition of PPGs and their valuable contribution is :-

"We realise the importance of the patient voice in the NHS and recommend it is made a statutory requirement for all GP practices to have a patient participation group in the new arrangements."

The full report has now been posted on our website and it does make interesting reading in light of the impending changes proposed by the Government.

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Further N.A.P.P. Developments

The NAPP Board has invited Stephanie Varah, appointed last September as Director for National Development, to become the new NAPP Chief Executive. This decision was taken following a recent internal review of NAPP's priorities and capacity to move forward in the new health and social care environment. Stephanie is currently working as CEO on a part-time basis supported by NAPP trustees.

With Stephanie's input NAPP has increased its involvement and profile in many initiatives at a national level raising awareness of the excellent work of PPGs and the important contributions PPGs can make at a practice and wider community level.

NAPP has succeeded in:

- Developing a close working partnership with the new Chair of the **Royal College of General Practitioners (RCGP)** Dr Clare Gerada, the RCGP Patient Liaison Group and RCGP Centre for Commissioning which has been set up to support GP commissioners. NAPP will be contributing to the development of an RCGP competency framework for GP's commissioners in partnership with this new Centre. NAPP has also been invited to attend RCGP Patient Liaison Group meetings on a regular basis bringing the wider perspective of frontline PPGs into this national group.
- Gaining agreement from the **RCGP Centre for Commissioning** to the inclusion of a leaflet about NAPP/PPGs in delegate packs at twenty two national RCGP workshops on effective commissioning.

Read the NAPP leaflet here www.napp.org.uk

Read more about the RCGP Centre for Commissioning here www.rcgp.org.uk

- Becoming a member of the **Department of Health Healthwatch Advisory Group**. (See Page 8)
- Collaborating with the Department of Health to start developing a resource for GP's, practices & PPGs to support the development of **Virtual PPGs** to help PPGs & practices reach out to & more effectively engage with the wider patient population. Virtual PPGs are already running alongside actual PPGs in practices operating through email networks or one example is at the John Kelso practice in Leek, Staffordshire. More information is available from Christine Botham PPG Chair or www.johnkelso.co.uk. The NAPP Virtual PPG resource will be launched on the NAPP website in the coming months.
- Securing NAPP input to and collaboration with the NHS Institute for Innovation and Improvement '**Productive General Practice Programme**' which aims to support general practices in realising internal efficiencies, while maintaining quality of care and releasing time to spend on more value added activities.
(FURTHER DETAILS pp. 6 &7)

STOP PRESS !

Please go to page 11 for news of important developments

Patient Reporting of Adverse Drug Reactions

An adverse drug reaction (ADR) is defined as a harmful or unintended reaction to a medicine, vaccine, herbal or complementary preparation taken at a normal or recommended dose. A medicine includes any drugs that have been used for prevention of illnesses such as vaccines, the diagnosis and treatment of any illness.

Why report a suspected ADR

In 1964 following the identification of the link between the drug Thalidomide and congenital deformities in babies, a voluntary reporting system, the Yellow Card Scheme, was established to report to the Medicine Health Care Regulatory Authority (MHRA) a suspicion that a medicine could have harmed a patient. The purpose of the Yellow Card scheme is to gather reports of suspected ADRs. While the scheme was initially open only to doctors and dentists, it has now been extended to include nurses, pharmacists and coroners.

Introduction of patient reporting

The Yellow Card Scheme was extended in 2005 to allow patients to report directly a suspected ADR to the MHRA. This has created the opportunity for UK patients and the public to be more engaged as active partners in their health care and as patients and members of the public to be listened to by the regulators- the MHRA. The results of patient reporting can, in the long run, only be positive. ADRs are costly to patients and their families and to the NHS. It is, therefore, important for the regulators, doctors, and pharmaceutical companies to know from patients, how suspected adverse drug reactions have affected them. The relationship between the patient and doctors and other healthcare professionals can be enhanced by increased openness and sharing information about suspected ADRs.

Patients can report a suspected ADR in the following ways: On a Yellow Card form, which can be found in pharmacies, GP surgeries or from the Yellow Card hotline by calling **freephone 0808 100 3352** during business hours.

The Yellow Card form can also be downloaded from the MHRA website www.mhra.gov.uk/safety, to print and complete. The form should be returned to the address at the bottom of the form. No stamp is needed, electronically from MHRA website or by telephoning **freephone 0808 100 3352** during business hours.

N.B. Although the scheme is referred to as patient reporting, any member of the public can report, but they must provide a name and contact details. Reports can also be made on behalf of others, for example a parent, carer, or friend. By increasing public awareness of the extent of and problems created by ADRs, some ADRs may even be prevented.

NAPP Resources

NAPP is currently **reviewing all its resources and publications** to ensure they are still relevant and appropriate for the changing health and care system. This is likely to result in a slight re-shuffle and improvement of the NAPP website also the launch of some new materials as previously mentioned. We will keep you updated via our e-bulletin as things move forward.

Staying in touch and making a difference for patients! – N.A.P.P. Membership:

NAPP is entering an exciting new phase! Don't miss the opportunity to have your say and be involved in shaping the new NHS, ensuring high quality patient care.

The role and potential of PPGs as partners supporting GP's in everyday patient care and in making strategic decisions about service provision has never been more important. **Ensure your PPG is in touch with developments both locally and nationally through the NAPP grapevine** by keeping your membership up to date.

In recognition of the structural changes in the NHS - NAPP has needed to review its membership arrangements and affiliation policy. Affiliating to NAPP offers many benefits to members. NAPP has reviewed its membership packages in light of the governments' new arrangements to ensure that support is appropriate, effective and tailored to meet members' needs in the new climate.

NAPP is working towards the existence of a PPG in every practice in the country – an aim shared by many GP's and key stakeholders – **a nationwide NAPP**

membership of PPGs, practices and Consortia working together can really make a difference for patients! Help us to achieve this vision by encouraging neighbouring practices, PPGs and your Consortia to become NAPP members.

Members support packages are available as follows:

- Individual GP Practices/PPGs – support to individual patients, GP's practice teams & existing PPGs in establishing and maintaining effective PPGs. Helping practices meet their new GP Contract Patient Participation requirement
- GP Consortia – to include support tailored specifically around the commissioning agenda in building meaningful and effective partnerships with PPGs. Also support to PPG district networks.
- PCT Clusters/Individual PCT's – to include support tailored around implementing the new GP Contract Patient Participation requirement & transition to GP led commissioning
- Individual patients – regular communications and updates from NAPP

More information on how to join NAPP and detailed support available to affiliate members can be obtained from Edith Todd at admin@napp.org.uk or Tel: 01932 242350.

Getting things moving on the ground

Whilst it is imperative that NAPP ensures a voice for and recognition of PPGs at a strategic level in the new national policy context especially in relation to the

development of Healthwatch and GP led commissioning, NAPP also recognises the importance of continuing to provide **high quality support and information to PPGs on the ground.**

Many PPGs are already getting involved in arrangements for GP led commissioning being developed in their localities. Whilst we understand that not all PPGs or PPG members may wish to get involved in commissioning activities it is important to recognise that **the new commissioning proposals are a major opportunity for PPGs** to shape local services by raising awareness of patients' needs, priorities and perspectives and ensuring these insights are integrated into decisions made by GP consortia.

PPGs are extremely well placed at the heart of general practice to gather patients' views about services, local needs and priorities for the future. Patient feedback can help commissioners target resources more effectively and ensure services are responsive to local need.

To help PPGs and GP commissioners become effective local partners NAPP is in the process of organising with the support of Strategic Health Authorities a series of **regional events** which will aim to:

- To support implementation of the new GP Contract Patient Participation requirement for a PPG in every practice
- Bring local PPGs, PPG district networks, emerging GP consortia including Pathfinders and Patient & Public Engagement 'early adopter' sites and PCT clusters together to share experiences/practice, start building relationships & networking opportunities for moving forward etc.

- Help NAPP make contact with Patient Participation Groups across your region & introduce them to the new commissioning agenda including an overview of things in your patch, any good practice e.g's where PPGs already involved in development of new arrangements etc
- Get a sense of the support PPGs may need to effectively engage with GP led commissioning in your area e.g forming into networks, identifying possible PPG champions who may know more & wish to be involved more in commissioning etc
- Provide support & information to GP commissioners/consortia in your patch about effective engagement also how NAPP and PPGs can support commissioning

We will let you have further information and dates once these have been finalised. It is hoped the events can start very soon.

In the meantime, please let me have any information about your experiences to date of being involved in commissioning activities as they develop. Send your updates to stephanie@varah.plus.com and they may be used nationally as case study examples.

Developing regional PPG networks and champions

To help support and communicate with PPGs more effectively NAPP is keen to develop regional networks and contacts (PPG champions!) for PPGs across the country. We are aware that many groups are already networked across their regions. If you have a network in your region or are interested in helping to get one going in your area please get in touch with Stephanie at stephanie@varah.plus.com.

NAPP Annual Conference

We are hoping to get a regional network approach off the ground as we move towards the NAPP Annual Conference in June with a view to possibly launching a national PPG network, consisting of PPG representatives from each region, at the Conference.

The NAPP Annual Conference and AGM 2011 “ Patients Matter” will be held on Saturday June 11th at the Grange Hotel, Bracknell, Berkshire. A full programme and booking form is added as an insertion in the hard copies of this Newsletter. For online readers the form is available on our website. In case of any queries or clarification issues please contact Edith Todd at admin@napp.org.uk or Tel: 01932 242350

Promoting self care for everyday ailments

NAPP is working in partnership with the Proprietary Association of Great Britain (PAGB) which represents manufacturers of over-the-counter medicines and food supplements in the United Kingdom to support a campaign to help people to be confident in their self care choices in respect of minor ailments. A minor ailment is something you can diagnose yourself and treat yourself without seeing a doctor.

PPGs have an essential role in empowering patients to get the most out of health and care services. Groups help patients access and understand appropriate information to support shared and informed decision making about treatment, self care and lifestyle choices thereby promoting positive mental and physical well being and

improving individuals’ confidence and self esteem.

NAPP is to produce promotional materials for practices highlighting the role PPGs can play in supporting and empowering individuals to make an informed choice also giving people access to and advice on the different courses of action they can take. A round of regional events for practices and PPGs is also planned to promote the campaign. Further details will be available in the near future.

More information and the findings from a comprehensive research study ‘Making the case for self care’ can be found at www.pagb.co.uk

NHS Institute for Innovation and Improvement Productive General Practice Collaboration with NAPP

Productive General Practice (PGP) is a new programme from the NHS Institute which aims to support general practices in realising internal efficiencies, while maintaining quality of care and releasing time to spend on more value added activities that benefit patients and the practice. It is the latest in The Productive Series, which takes a modular approach and supports NHS teams to redesign and streamline the way they manage and work.

NAPP is collaborating with the NHS Institute on the development of the module within the programme that focuses on improving patient and carer experience. NAPP is specifically supporting this module development in relation to Patient (continued on page 7)

(continued from page 6)

Participation Groups (PPGs). This will include references through NAPP to guidance on how to set up a PPG, case stories and information about NAPP.

For access to news bulletins on progress with this programme development please click on this link

http://www.institute.nhs.uk/productive_general_practice/general/resources.html

Care Quality Commission Registration of GP practices:

From the 1st April 2012 NHS primary medical services must be registered with the Care Quality Commission (CQC). Providers that need to be registered are those that provide 'regulated activities' and whose sole or main purpose is to provide NHS primary medical services. Examples include GP practices, GP out-of-hours services and some walk-in centres.

The Health and Social Care Act 2008 introduced a new single registration system across health care and adult social care. All providers who carry on regulated activities will be required by law to be registered with CQC. To do so, they must show that they are meeting essential standards of quality and safety.

The CQC guidance about compliance: Essential standards of quality and safety can be read at www.cqc.org.uk/guidanceaboutcompliance

Regulated activities are set out in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. GP practices must register to provide each of the regulated activities they carry on. The

activities that are most likely to apply to primary medical services are:

- Treatment of disease, disorder or injury
- Diagnostics and screening procedures
- Surgical procedures
- Family planning
- Midwifery and maternity, and transport services, triage and medical advice provided remotely.

CQC is to run some GP registration pilots in the coming months and is keen to involve PPGs at pilot sites. Pilots will encourage practices to think about how they can work with PPGs and about establishing PPGs if none exist.

CQC will be interested to work with PPGs to think about how they might approach PPGs for feedback on their practice in relation to CQC essential standards. NAPP is working in partnership with CQC on these pilots and will have more information on proposed sites in the near future.

Please send your articles, news, activities, photographs etc for inclusion in our newsletter.

Your activities will always be of interest to fellow PPGs particularly if you've been involved in something innovative.

We are conscious that the Newsletter can become dominated by National issues when we would rather feature what is happening within the 'grass roots.'

Contact details are featured on page 10 within the Message from the Editor article.

Healthwatch Developments

NAPP is a member of the Department of Health Healthwatch Advisory Group (HWAG) NAPP Chief Executive Stephanie Varah recently attended the inaugural meeting. The HWAG will provide 'bottom-up' expert, practical advice and make recommendations to the Department of Health Programme Board about implementation of the Government's proposals for HealthWatch England and local Healthwatch.

The three key differences between the current LINK arrangements and the HealthWatch proposals are:

- a shift from participation to influencing the outcome of health and social care services;
- local voice to national influence;
- new functions adding individual to the collective.

The Advisory Group is not a forum to lobby for legislative change during the passage of the Bill in Parliament; but a Department of Health sponsored Group to advise the Programme Board about implementation of the programme.

The Advisory group will dissolve once HealthWatch England comes into being, following the Health and Social Care Bill receiving Royal Assent.

A Department of Health-led HealthWatch Programme Board will oversee implementation of the whole programme, working in partnership with the Care Quality Commission and Local Government.

Three key work streams were identified from the meeting which will be taken forward by sub groups of the HWAG membership. These were:

- Creating a vision for HealthWatch – designing and shaping the new organisation
- Working together - building and sustaining relationships in the new health reformed system
- Transition – building on the evaluation and learning from the implementation of LINKs.

Stephanie made the point at this meeting that it is extremely important that PPG's are formally recognised in their own right as an important component of the involvement and engagement architecture alongside LocalHealthWatch and HealthWatch England.

The unique role that PPG's play should be understood as distinct from that of LINKs and Local HealthWatch. PPG's and N.A.P.P should be fully integrated into all future policy planning, development and implementation as a key strategic partner.

The essential distinctions between PPG's and Local HealthWatch (LINKs currently) relevant to the new patient and public voice proposals are:

- PPG's focus on individual patients and GP Practices, LINKs focus on communities, particularly those 'hard to reach'
- PPG's have direct access to and gather feedback from individual patients about GP, primary care services and the Practice, LINKs gather feedback from the wider community on health and social care services
- PPG's focus on improving the quality of general practice and primary care based on patients' feedback, LINKs look for trends from feedback that

highlight the priorities identified by local people who use services and citizens resident in the wider area. PPGs already have the trust and respect of the practices in which they work.

Department of Health Pilot to promote effective patient and public involvement in GP commissioning

The Department of Health is engaging with a number of pathfinder and leading consortia, their PCTs and Local Authorities to understand their early plans for Public and Patient Engagement (PPE).

The pilot aims to ensure that consortia have processes and structures in place to ensure that GP consortia:

- have effective and appropriate means to engage patients and public in *the everyday working* and key commissioning decisions of the consortia.
- have processes and structures in place to ensure the patient and public voice is represented in commissioned outcomes for patients

PPE pilots are being run by consortia in the following areas:

Nottingham Principia; Lincolnshire; Stockport; Leodis (Leeds); Oldham; Manchester; Central & Eastern Cheshire; Central Lancashire; Bolton; Ashton, Leigh & Wigan; Halton & St. Helens; Solihull; Wandsworth; Sandwell; West Sussex; Buckinghamshire; Fortis (Essex PCT); NHS Cambs & Peterborough; Hertfordshire; Hertsmere (Hertfordshire); Horizon (Bedfordshire PCT); North Staffs; Wyvern (Somerset PCT); Brighton

NAPP is encouraging PPGs in pilot areas to get involved with this pioneering project. If your PPG wants to know more,

contact NAPP at admin@napp.org.uk

Tel: 01932 242350

or stephanie@varah.plus.com for a full list of contacts for the pilots.

Become a lay member of the familial breast cancer guideline development group

The [Patient and Public Involvement Programme](#) (National Institute for Health & Clinical Excellence) and the [National Collaborating Centre for Cancer](#) are looking for applications from patients, carers and/or family members to sit on the group to carry out a partial update of [NICE clinical guideline 41](#) on Familial breast cancer: the classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care (itself a partial update of CG14).

Applications are welcome from anyone who

- has or has had breast cancer and who has one or more close relatives who have had breast or ovarian cancer
- has one or more close family members with breast cancer (close family members include sister, brother, parent; and perhaps others on the same side of the family, such as uncles and aunts or grandparents)
- is or has been the carer of a person with familial breast cancer
- is a policy officer from a relevant patient organisation
- has an understanding of, and a willingness to reflect, the experiences

and needs of a wide network of relevant people (perhaps as a member of a support group or organisation)

- time to commit to the work of the group: attending meetings, background reading, commenting on draft products etc.
- good communication and team working skills

Health professionals will be well represented on the group so we are looking for someone **without** a health professional background.

Members of the guideline development group representing patients' and carers' interests are paid an attendance fee and travel expenses are also reimbursed. The Patient and Public Involvement Programme will provide these members with dedicated and on-going support throughout their time on the Group.

For more information, and details of how to apply please see www.nice.org.uk/getinvolved/joinnwc/LayMemberFamilialBreastCancerGDG.jsp

The closing date for this vacancy is 5pm, 3 May 2011 (please note the proximity to two bank holiday weekends).

Please contact David Bevan if you have any questions or wish to discuss the role further;

David Bevan
Patient and Public Involvement Programme
NICE
MidCity Place
71 High Holborn
London
WC1V 6NA

Email: ppiprecruitment@nice.org.uk

Message from the Editor

The last issue of the newsletter (Autumn/Winter online edition and Winter 2010/2011 in A5 monochrome) were pilots to ascertain whether the format etc. would be acceptable and applicable comments were requested. Comments received to date have been positive and we intend to publish the Spring edition in hard copy in a similar format. If you require the necessary passwords to view the full colour recent edition online please email a request to Edith at edith.todd@napp.org.uk.

We have received various communications from our affiliates on diverse matters and we would like to share some of the content of those with our affiliates. We also view the inclusion of a **'Letters from Affiliates'** page as being a valuable and worthwhile feature. Many problems which confront PPGs might have been experienced by other groups who may have advice to impart. Alternatively you may have views on current topics that you would like to air to a wider audience. Obviously without your input this will not happen so please submit your articles views or comments by email or letter to the Newsletter Editor, Danny Daniels, at danny.daniels@napp.org.uk or mail to

21, Croffta, Dinas Powys, Vale of Glamorgan, CF64 4UN

GOOD NEWS FOR PATIENTS

A new Patient Participation requirement for GP Practices:

The Department of Health has recently released details of the National Directed Enhanced Scheme (DES) **to improve patient participation** as part of the recent changes to the GP contract for 2011/12.

From April 2011 for two years, GP practices will be required to promote the proactive engagement of their patients through 'Patient Reference Groups' and to undertake local surveys. Key requirements for Practices are to:

- develop a structure that gains the views of patients and enables the practice to obtain feedback from the practice population, e.g. a patient reference group
- agree areas of priority with their patient reference group
- collate patient views through a patient survey
- agree an action plan with their patient reference group
- publicise the results of the patient survey
- publicise the actions taken and what is achieved as a result.

Around £60m of released investment will be available to practices, provided that they successfully meet these requirements, which is equivalent in total to £1.10 per registered patient. The detailed guidance for this has now been published & can be found at the link below:

<http://www.nhsemployers.org/PayAndContracts/GeneralMedicalServicesContract/LatestNews-GMS/Pages/NewQOFGuidancePublished.aspx>

NAPP is collaborating with the Department of Health to offer support to practices across the UK in meeting these requirements. More details are available on the NAPP website.

N.A.P.P. 32nd Annual Conference **Patients Matter**

*Developing a stronger voice for patients
in raising the quality of healthcare*

Saturday 11th June 2011

Registration from 9.30 am

**The Grange Hotel, Bracknell,
Berkshire, RG12 1DF**

Who should attend?

PPG members,
Practice Managers, GPs,
Practice Nurses, PCT PPI leads,
GP Consortia Members,
LINKs managers and members

Why attend? Last year's delegates said

"Refreshing!"

"This has been a revelation! I have learned so much, my head is buzzing"

"I wish I had come three years ago before we started the PPG"

"Would recommend to other groups"

"Well organised, friendly and very useful in exchanging views and practices"

"Very interesting and informative"

"A very worthwhile event which deserves greater participation from PPGs!"

For programme and booking form:

Download from www.napp.org.uk,

email admin@napp.org.uk

Call 01932 242530.

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Official partner to N.A.P.P.

There are now approximately 600 PPGs affiliated to N.A.P.P. Over the last eighteen months the numbers of new members has accelerated at a greater rapidity than at any other time since N.A.P.P. came into being over 30 years ago.

Can you possibly let us know if you are a member of a local/regional networking group in your area. It would also be helpful to find out if your network is composed solely of N.A.P.P. affiliates or not. This in turn will assist in the strategy of forming a strong networking development for all PPGs as discussed on pp. 4,5 or 6 of this newsletter.

A brief email notification with details of your network to admin@napp.org.uk would be much appreciated.

Disclaimer *The views expressed in this newsletter do not necessarily represent the views of N.A.P.P. N.A.P.P. accepts no liability for any inaccuracies or omissions in this newsletter. Content of the newsletter is for general information. Readers should consult appropriate health professionals on any matter relating to their health and well-being.*