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E-Bulletin from

National Association for Patient Participation

Issue Number 63 May 2012

1. Knowing your QOF from your QIPP (or QQIPP)*

One of the first challenges presented to new PPGs and their members is understanding the numerous acronyms used in the NHS. The NHS Confederation** has published a new [acronym buster](#) designed to help you quickly get to grips with these, and take the online quiz to test your NHS knowledge. Set out alphabetically so you can easily look up what a set of initials stands for, the new buster includes acronyms for both existing and new NHS organisations. * **Answers at the foot of page 2**

** The NHS Confederation is the membership body for the full range of organisations that commission and provide NHS services

2. Tracking Parkinson's Research project: 3000 volunteers wanted

On April 16th, the start of Parkinson's Awareness Week, Parkinson's UK launched the biggest in-depth research study tracking people with Parkinson's ever mounted anywhere in the world. If you or a family member has been diagnosed within the last three years or is under the age of 50, both of you could contribute to this new research study. Parkinson's UK is investing over £1.6 million into the new [Tracking Parkinson's research study](#) to unlock further secrets about Parkinson's and to boost the chances of finding a cure. They need 3,000 volunteers to take part in its groundbreaking clinical study, both those recently diagnosed (in the last 3 years) and those aged under 50 at diagnosis.

They will also be asking a smaller number of brothers and sisters of people with Parkinson's (who are enrolled in the study) to participate. If you're not eligible yourself please help by telling others about it.

3. Results of the latest Inpatient Survey

CQC (if you don't know, try the acronym buster) has published findings from the inpatient survey 2011, which looked at the experiences of over 70,000 people who were admitted to NHS hospitals around England. The results of the survey will be used by NHS Trusts to improve their performance and to understand their patients' experiences. CQC will use the results to support their regulatory, compliance and monitoring activities. To find out how your local are service performed, view the [A-Z list of inpatient survey results by NHS Trust](#)

4. Healthtalkonline People's stories: see, hear and read their experiences...

So many urgent questions arise from diagnosis of a serious health condition and living with the symptoms - How is this illness going to affect my life? Can it be cured? How do I tell my friends children and family? What is it really like to have chemotherapy? Why did no-one tell me I'd feel like this? What should I do to be healthier?

[Healthtalkonline](#) is the website of the DIPEX charity. [Youthhealthtalk](#) is aimed specifically at your people. Patients, families, carers and healthcare professionals can benefit from and share in experiences of over 60 health-related conditions and illnesses of more than 2,000 people. You can read about them, watch video or listen to audio clips of the interviews, and find reliable information about specific conditions, treatment choices and support. The information on Healthtalkonline relies on external funding from ethical sources (i.e. not from pharmaceutical companies) and is based on qualitative research into health experiences, led by experts at the University of Oxford. Since its inception in 2001, the Health Experiences Research Group has been involved in a major programmed of qualitative research to understand people's experiences of health and illness

5. Improving the quality of life for people living with dementia.

One in three of us who live to 65 will have some form of dementia before we die. A million people in the UK will be living with the condition by 2021. The Design Council in partnership with the [Department of Health](#) has funded and supported the development of five innovative new design solutions that can improve the quality of life for people living with dementia, and aid the development of dementia friendly communities. [Living well with dementia – Design Council to launch new projects](#) These initiatives could make the difference between simply **living** and **living well**.

6. New guidance on the Cancer Drugs Fund

New [guidance](#), announced on 23rd April, is intended to help speed up access to the drugs patients need. It will mean in most cases patients will be able to access drugs within a matter of days of an application being made to the fund. The Department of Health has worked with NHS colleagues to review the 2011, taking into account public feedback from cancer charities, to ensure cancer patients are able to better access the drugs they need.

7. Impact of NHS Constitution: independent group appointed.

On 25th April, Health Secretary Andrew Lansley announced the formation of the NHS Future Forum Working Group on the NHS Constitution, a new independent expert panel which will contribute to a Government report. The group, which met that week, is made up of medical professionals, patient champions, staff representatives and charities. The Future Forum group will explore whether there is any scope for strengthening the NHS Constitution to support high quality services for patients. A public consultation later this year will give patients and staff the opportunity to have their say about what can be done to improve and reinforce the Constitution. [Read more](#)

8. N.A.P.P. Conference fully booked

'**Empowering Patients, Supporting Practices**' on May 26th in Manchester is now fully booked. The keynote speech by Niall Dickson, Chief Executive of the General Medical Council will be 'Striking a new deal with patients in support of a quality service'. As always, we expect to provide information and networking opportunities for patient and staff members of PPGs with each other and with other patient related organisations and staff from PCTs and CCGs. View the programme [here](#).

9. Corkill Award: N.A.P.P. of the Year

The short list has been chosen, and the winner of the award, sponsored by EMIS, of a plaque and a cash payment of £500 to the successful Group, should be announced by May 12th and will be posted in the N.A.P.P. website.

10. Reminder: Please forward this bulletin to your fellow members as promptly as possible. We are sorry that we do not have the capacity to send hard copies of e-bulletins. All previous e-bulletins and Newsletters are available on our website at www.napp.org.uk. The latest issue of the Newsletter - Spring 2012 edition - is in the Members' Area. Login details from edith.todd@napp.org.uk

* **Answers:** QOF quality and outcomes framework
 QIPP quality innovation productivity prevention
 QQUIP quest for quality and improved performance

*Stephanie Varah,
Chief Executive
May 2012*