



# Patients Matter

Charity No. 292157

N.A.P.P. Quarterly Newsletter.

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Involved Patients, Excellent  
Care  
**Patient Participation Week**  
**June 1<sup>st</sup> – 8<sup>th</sup> 2013**

The first ever **National Patient Participation Week** will run from June 1<sup>st</sup> - 8<sup>th</sup> 2013.

The week is organised by the **National Association for Patient Participation, (N.A.P.P)** a national charity, formed in 1978. Uniquely placed as the only umbrella body for patient-led groups in primary care, N.A.P.P has over 30 years' experience in promoting, supporting and developing Patient Participation Groups (PPGs). There are now over 900 groups affiliated to N.A.P.P, representing at least ten million patients across the UK.

Working in partnership with GPs and practice teams, Patient Participation Groups ensure the patients perspective is at the heart of local provision so that services are of high quality and continuously improve. Groups also provide practical support in the surgery, foster improved communication between the practice and its patients and help patients to take more responsibility for their health. (cont. p.2)

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## A 'Champion' Day Out

At a time when the NHS in England is undergoing significant change, Patient Participation Week aims to highlight the importance of patient participation to achieve excellence in care for all patients. During the week Patient Participation Groups across the UK will be holding a wide range of events to increase public and professional awareness, including working with local media organisations to spotlight success in patient participation.

A national media campaign with contributions from leading health stakeholders will also highlight the value of these 'grass roots' groups and the important role they play in driving up the quality of care. The week will culminate in the N.A.P.P annual national conference, this year held in Bristol, entitled 'Primary Care in the digital age: What does this mean for patients, quality and continuity of care' which will explore the impact of new technology on patients relationships with health services, and highlight best practice in patient participation.

Information packs to support PPGs and practices get involved are available from the N.A.P.P website. Packs include templates for posters and press releases also ideas about possible activities.

There is also a mock- up of a completed poster on the website to give you some ideas concerning possible content. Also included on our website you will find a list of hints for writing a Press Release to advertise your forthcoming programme for the week. We've reproduced it here in case you wish to keep it as a source for future reference.

Thirty PPG members who have participated in the NAPP PPG Commissioning Champions Pilot Project recently enjoyed a celebration lunch and received certificates from John Bewick OBE Director of Authorisation and Commissioning Development for the NHS Commissioning Board to mark their achievement as Commissioning Champions.

The PPGs represented four pilot site PPG Networks from South Cheshire, Milton Keynes, North Staffordshire and Leicester City. A NAPP Commissioning Learning Resource was also launched at the event which will be available to PPGs, PPG Networks, Clinical Commissioning Groups and Local Area Teams of the NHS Commissioning Board to help engage with the new commissioning system patients and the public understand and also to help build relationships and accountability between commissioners and the communities they serve. More information is on the commissioning pages of the website.

**Our Website is one of the main link of Resources for our affiliates. Since we upgraded the site in January of this year we are experiencing an upsurge in visits by PPGs. Don't miss out. Obtain your password by contacting [admin@napp.org.uk](mailto:admin@napp.org.uk)**



*The following news article featured in our February e-bulletin.*

A survey, undertaken by Appello, has highlighted that delegates at the recent International Telecare and Telehealth Conference think patients value 'independence' and 'reassurance' most about telehealth.

Appello were keen to discover what people working in the industry felt service users valued most about their service. Conference delegates, and those following the event on Twitter were asked, to complete the following statement: "I believe what service users value most is...". From the results Appello have created a video presenting the findings. The results show that the most commonly used words by delegates were; 'independence', 'reassurance', 'peace of mind' and 'convenience'.

Suzette Simon, from the London Borough of Merton, who is featured in the video, revealed: "I believe what service users value most is having someone there 24 hours a day, and knowing that they can live independently".

Carl Atkey, head of Appello said: "As a patient focussed telehealth provider we wanted to get real insight into how people in the telehealth and telecare industry think patients perceive telehealth. Words like 'independence' illustrate that telehealth and

telecare can provide a real life-line to the people at the heart of the service, who often have no one else to rely on or who would like to have greater control over their long term condition."

**We are keen to add more views, so if you would like to tell us your opinion, tweet @talk2appello**

## **Building Health Partnerships Programme launched**

Funding has been announced to help communities to build partnerships with CCGs, to improve health service delivery. 12 areas will receive up to £50,000 each to support the Building Health Partnerships programme, which will develop and share best practice between health commissioners and the voluntary, community and social enterprise (VCSE) sector.

The programme will see partners develop new ways of working together, identifying gaps in health services and considering how they can contribute to filling them. The 12 areas are:

**Bristol; Croydon; City & Hackney; Dudley; Durham; Hampshire; Bradford & Airedale; Manchester; Shropshire; Staffordshire; Swindon; and Wakefield**

They will also receive training support to improve engagement with health commissioners. The Building Health Partnerships programme is being delivered in partnership with the National Association for Voluntary and Community Action (NAVCA), Social Enterprise UK, the Institute for Voluntary Action Research and the NHS Commissioning Board.

Tim Kelsey, the NHS Commissioning Board's national director for patients and information, said: "The NHS can't operate in isolation. The NHS Commissioning Board wants to foster a culture of openness and partnership with people who use the service and the organisations that support them. This includes partnerships with the voluntary sector, which are critical to improving outcomes for people.

"We want to work with you to design the ways we can have great insight. Your organisations have experience, insight, data and knowledge that is an important part of how commissioners can improve their understanding of what services are needed and how to support people to use those services

"Local communities and voluntary sector partnerships need to be at the heart of how the new system operates. Increasing participation and supporting active citizens is essential, not just an added extra."

Ceri Jones, head of policy and research at Social Enterprise UK, said: "This programme aims to bridge the gap of understanding between the voluntary, community and social enterprise sector and the new CCGs. Groups of local clinicians are going to be responsible for commissioning for the first time and it's important they understand what our sector can bring to communities.

"Social enterprises and the voluntary sector have been delivering quality health and social care services for years, including to the hard-to-reach, and we need to ensure they continue to be commissioned to meet the needs of people across England."

Neil Cleeveley, director of policy and communications at NAVCA said: "Involving charities, community groups and social enterprises in the design and delivery of health and social care services improves local services and offers value for money. This programme will help commissioners and voluntary organisations work together to bring real and lasting benefits to local communities. Indeed, the lessons we learn

have the potential to make a difference beyond health and care services to influence the commissioning of all public services."

Tell us what you think – have your say below, or email us directly at

[opinion@nationalhealthexecutive.com](mailto:opinion@nationalhealthexecutive.com)

## **N.A.P.P. 10 Minute Guide on the use of Social Media**

We have recently been made aware of issues concerning the use of Social Media from one of our affiliates. A rapid response to the PPG in question was made in order to assist in the promotion of satisfactory outcomes in this instance.

Nevertheless we are conscious that we need to formulate a code of practice for PPGs to either adopt entirely or customise to specific needs. We are currently working on such a guide which will be circulated and placed on our website for access by our members in the very near future.

## **Primary Care research hits patient recruitment milestone**

Primary care has reached a recruitment milestone in research with over 500,000 patients now taking part in studies looking at health promotion, disease prevention and common conditions dealt with by general practitioners, dentists and pharmacists.

Created in 2007, and funded by the Department of Health, the National Institute for Health Research Primary Care Research Network (PCRN) provides healthcare professionals with the practical support they need to make clinical studies happen in a primary care setting in the NHS.

Commending those involved, Dr. Patricia Ellis, Assistant Director of PCRN said: "Reaching

this milestone is a great achievement. Our vision is to improve treatment and services for patients by working in partnership with researchers and primary care practitioners, to conduct important and relevant research in the NHS. I would like to congratulate Network staff, researchers, general practices, pharmacists, dentists, plus a wide range of other primary care professionals and of course patients for their dedication to research. We are working towards making involvement in research a routine part of clinical practice so that patients wherever they may live can be offered the opportunity to take part in improving the health of the nation.”

Professor Paul Wallace, Director of PCRN, looks back over the past seven years:

“A key reason for our success in recruiting so many patients is the enthusiastic response which we have received from general practices and other primary care providers around the country. Over the seven years since PCRN was established, we have seen a steady growth in the number of practices which have engaged with the Network, and we now calculate that well over half the practices in England have been actively involved in at least one of our studies. This remarkable achievement is a testimony not only to the participating practices but also to the excellent PCRN teams in each of our eight regional networks.”

As primary care is the first point of contact in the health care system, the PCRN research portfolio includes studies across all clinical areas and on screening and prevention, diagnosis and acute care, care of patients with long term conditions and end of life care.

Direct participation in a study is not the only way in which patients can get involved in research. Tracey Johns, PCRN Patient Public Involvement Manager said:

“Research involves many different activities and patients can get involved without having to physically take part in a study. Patient experience and feedback is extremely valuable

to help shape how we do research. We encourage patients to ask about research when they visit their GP.”

For further information about primary care research visit

[http://www.crnc.nihr.ac.uk/about\\_us/pcrn](http://www.crnc.nihr.ac.uk/about_us/pcrn)

## **It's OK to Ask Campaign**

N.A.P.P. is one of many organisations around the country that are supporting “It’s OK to ask” – a new campaign led by the National Institute for Health Research to encourage patients to ask their family doctor, nurse or consultant about clinical research.

Clinical research is the way in which we gather evidence to improve treatments for patients. Promoting, conducting and using clinical research to improve healthcare is one of the key principles of the NHS, and the new Constitution for NHS England contains a pledge to inform patients of research studies in which they may be eligible to participate

In many cases doctors will approach patients and carers about taking part research, but the NIHR also wants patients to feel empowered to ask about it, to keep research at the top of the NHS England agenda.

In a recent consumer poll, less than 21% of patients and the public said that they would feel confident asking their doctor about research opportunities – a low number.

That’s why the National Institute for Health Research (NIHR), with our support, is promoting the fact that it’s OK to ask about clinical research.

If you have a medical condition and are undergoing treatment, you can join the campaign by asking your doctor, nurse or consultant about clinical research, and whether it might be right for you or someone you care for.

The NIHR would then like you to let them know that you took part by logging that you asked about research, along with what response you received and any other comments you want to make, on their campaign social media sites, or by email or phone.

By measuring your responses to the “OK to ask” campaign the NIHR will be able to let clinicians know that patients are interested in research. It will also help them to see where the response to patients who want to take part in research could be improved. If you ask your doctor about clinical research, please support the campaign by telling the NIHR what happened in one of the following ways:

On Facebook at

[www.facebook.com/NIHRoktoask](http://www.facebook.com/NIHRoktoask)

On Twitter: @OfficialNIHR using #NIHRoktoask

By email to [oktoask@nihr.ac.uk](mailto:oktoask@nihr.ac.uk)

By telephone: 0300 311 99 66

Further information on the OK to ask campaign can be found online at

[www.crncc.nihr.ac.uk/oktoask](http://www.crncc.nihr.ac.uk/oktoask)

## **Good News From Wales (but no room for complacency)**

The number of people dying from heart disease in Wales has more than halved in the last three decades, according to new figures released on May 7th

Statistics from the British Heart Foundation show that around 4,300 people now die from coronary heart disease in Wales each year, including 2,500 men and 1,800 women. In 1981 more than 9,600 people from Wales died of coronary heart disease – around 5,600 men and 4,000 women.

But the charity has warned against complacency, saying the statistics should not mask the “devastating burden” that heart failure still has on patients and their families. Even though heart attack deaths in Wales are decreasing, the charity warned there is little evidence the same is true of heart failure.

The most recent audit found that as many as 70% of heart failure cases are caused by coronary heart disease and an estimated 44,000 people now live with heart failure in Wales.

Heart failure occurs when so much heart muscle is damaged by the heart attack that the heart cannot pump blood around the body as well as it should. Three quarters of people with severe heart failure will not live beyond five years.

The charity has launched its Mending Broken Hearts appeal to raise money for research into the condition.

Professor Peter Weissberg, medical director at the British Heart Foundation, said: “We’re undergoing an unprecedented period of change when it comes to heart health in Wales. “It is pleasing that decades of British Heart Foundation funded research has contributed to the dramatic fall in heart attack deaths over recent years. But this means that more and more people are surviving heart attacks with damaged hearts and there is now an urgent need to find ways of reversing that damage.

“Our scientists are making great strides in this fight against heart failure, but success will require much more money and much more research to ensure that this momentum is not lost.”  
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On the rate of heart disease in Wales, Tim Kinnaird, consultant interventional cardiologist at Vale Healthcare, said: "Many factors contribute to this including lifestyle factors such as smoking, obesity but also other conditions including high blood pressure and diabetes

. "Although major initiatives to improve health behaviour are likely to make an impact of the death rates from heart disease in Wales it is important that further investment into heart services takes place to support and develop future treatments."

Health Minister Mark Drakeford has launched the Welsh Government's delivery plan for heart disease in a bid to improve services for patients following a three-month consultation which ended in October.

The plan is part of the Welsh Government's commitment to reduce the incidence of cardiac disease in Wales as outlined in its five-year Together for Health vision for the NHS published in November 2011. Under the plan, heart disease will be prevented through educating people about healthy lifestyles with an emphasis on the consequences of smoking and drinking alcohol and the benefits of exercise.

Another aim is for detection of the disease to be done quicker by identifying those at risk of avoidable cardiac disease and providing effective treatment.

A Welsh Government spokesman said: "While we welcome the figures that show death rates from heart disease are falling in Wales, the Welsh Government is aware it is still a major killer, especially for people living in our poorer areas.

"This is why the Health Minister has launched 'Together for Health – A Heart Disease Delivery Plan' to minimise preventable heart disease and ensure that those affected by any kind of heart disease have timely access to high quality aims.

## Good Advice from Scotland

Washing your hands is one of the most effective ways of reducing the spread of infections such as norovirus and flu, according to Scotland's Chief Medical and Chief Nursing Officer. Over this winter, there have been 35 deaths from flu and it is estimated that every year up to one quarter of the population may be affected by an episode of norovirus. Sir Harry Burns and Ros Moore are urging people to follow a few simple steps to help reduce the spread of bugs. Recent statistics show that 95 per cent of NHS staff are complying with hand hygiene guidelines, and this has played a part in helping to reduce the number of healthcare associated infections in hospitals.

Latest figures show that rates of C diff in people over 65 have fallen by over 82 per cent since 2007, which means they are at their lowest levels since recording began, and MRSA has reduced by 79 per cent over the same period. Chief Medical Officer Sir Harry Burns is urging people to follow good hand hygiene practice to help reduce the spread of bugs in the community. He said: "Good hand hygiene is one of the best ways to reduce the spread of infection and there is no excuse for people not to wash their hands.

"By following a few simple precautions you can help to protect yourself and your family from bugs.

“We have seen a dramatic reduction in healthcare associated infections in hospitals, which also coincides with an increase in hand hygiene compliance rates, and shows that hand washing is playing an important role in reducing the spread of infection. It is particularly important when you are in hospital – whether you are a member of staff, visitor or patient – that you wash your hands properly to help prevent the spread “of infection.”

Chief Nursing Office Ros Moore added: “Washing your hands with soap and warm water is the single most important thing you can do to help reduce the spread of infections and help protect you, your family and those around you. Parents should also encourage their children to wash their hands by showing them how to do it, to help ensure this becomes a lifelong habit. It takes at least fifteen seconds to wash your hands properly – try singing 'Happy Birthday' twice through as a rough guide for how long it should take.”

- Hand washing should be part of everyone's daily routine especially:
- Before eating or handling food
- After using the toilet
- After blowing your nose, coughing or sneezing
- After touching animals or animal waste
- After handling rubbish
- After changing a nappy
- Before and after touching a sick or injured person
- Before and after visiting a hospital ward (remember alcohol-based hand rubs are also provided).

The logo for emis, featuring the word "emis" in a bold, blue, lowercase sans-serif font. A registered trademark symbol (®) is located to the upper right of the letter 's'. The logo is centered within a rounded rectangular border.

Sponsor of Corkill PPG of the  
Year Award

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