

Autumn 2009

Putting PPGs on the Map

The Growing Patient Participation campaign, funded by the Department of Health in England, has made great progress in developing resources to promote and support PPGs. These can be found at www.growingppgs.com. You can also register there to receive regular free updates by email.

One of the next steps is to consolidate this work by *Putting PPGs on the Map*. So the campaign website will host a map with every English GP surgery on it. Practices with a PPG will then be specially identified. Those PPGs will also have the opportunity to enter some basic information about themselves if they wish. As a result, it will be easier than ever before for PPGs to identify their neighbours and to see the areas in which they are active.

The map will also highlight the numbers of PPGs and how many people across the country are working actively with their practices to promote health and local health services. The planned NAPP sponsored cycle

ride (see page 7) will also contribute to this theme of *Putting PPGs on the Map*.

A further feature of the campaign is the growing number of case studies that have been captured on the campaign website. These illustrate the rich diversity of PPG activity. We are also in the process of capturing stories from Primary Care Trusts across England describing how they are supporting and promoting PPGs on their patch. These will be presented in a one-off newsletter that is currently being designed.

One final development worthy of note. NAPP is preparing a training course designed specifically for people who are, or want to be, active in promoting PPGs in their area. This will be suitable for PCT professionals, practice staff and lay people. We have bid for funding to support this initiative but we may be able to deliver the training even if that bid is not supported.

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Empowering patients with hearing limitations

SignHealth, a deaf charity dedicated to bridging the gap and reducing the inequalities between patients with hearing limitations and those without, recently joined forces with Patient.co.uk to carry out a survey which highlighted the barriers in healthcare experienced by deaf people.

An estimated nine million people in the UK experience hearing limitation and 70 per cent of people over 70 have some hearing loss. 525 deaf and hearing impaired patients took part in the survey which revealed that it was not just the profoundly deaf who experience problems. 64 per cent of respondents considered themselves to be moderately deaf – yet they reported the same problems as the profoundly deaf, who made up 11 per cent of the sample.

As a result of the survey, patients with hearing limitations highlighted feelings of frustration and embarrassment as well as the following issues:

- appointments were often missed as patients struggle to hear their name being called
- communication problems leading to missed symptoms
- lack of time to exchange full information in a consultation.

This result corresponds with previous research from SignHealth which discovered that a third of deaf patients leave medical consultations unaware of how much medication they should take, and many leave a consultation

misunderstanding the advice given.

Steve Powell, Chief Executive of SignHealth commented, "This is a timely survey that reveals the breadth and depth of problems faced by deaf patients across the UK. It reinforces our findings from the last two years' NHS GP Patient surveys and strengthens our commitment as an organisation to campaign for better healthcare for deaf people. "It is moving to hear the respondent's comments; many of them felt both frustrated and embarrassed at the difficulties they were experiencing, often on a regular basis."

SignHealth have proven their commitment by continuing to fund the SignTranslate programme for the second year - providing doctors and deaf patients with a simple way to communicate easily and quickly.

The SignTranslate programme is simple - the GP chooses what they want to ask the patient from a list of predefined questions and the program shows a video clip of a person signing the question. The deaf person normally answers with 'yes' or 'no', but sometimes selects from a list of on-screen answers or points to a diagram on the screen. There is also an option to add subtitles so patients who do not understand sign language can benefit from the service.

In addition, Patient.co.uk – run by EMIS - offers an extensive amount of health information. Patient.co.uk is a simple to use resource for information on health, disease and lifestyle matters, contact details of support organisations and downloadable medical leaflets and much more.

GPs can link directly to Patient.co.uk to download Patient Information Leaflets during a consultation, enabling the patient to gain a fuller understanding of what was discussed during their consultation.

To find out more about SignTranslate please visit www.signtranslate.org.uk or for SignHealth visit www.signhealth.org.uk



Fuel Poverty - A Role for PPGs

This article was submitted by Royce Franklin Vice Chair of N.A.P.P.

Fuel poverty is defined as the inability to heat your home to a comfortable, healthy standard. A household in fuel poverty can be described as one which has to spend more than 10% of its income in order to achieve temperatures of between 18° and 21° centigrade in all main living areas.

Currently households are spending on average £1243 on energy in their homes compared with £580 in 2005. An increase of over 109%.

A lack of warmth in homes affects those with long term illnesses such as arthritis, cancer, diabetes and depression. In some instances it leads to isolation where an individual who can't afford to heat a home does not wish to invite guests into a cold home. That person becomes isolated and depressed and in some instances a recluse.

It can also impact on a child's education where the child can't concentrate because of cold and/or has a disproportionate time off school through illness.

A fundamental task for all PPGs is to act as the conduit between patients and the practice. Part of that process is the identification of particular problems faced by patients. Fuel poverty can certainly be one, irrespective of the area which the practice and PPG serve.

Oldham is one of the most deprived towns in the country. Saddleworth is part of both the same Borough and Primary Care Trust. In relative terms it is affluent. In such circumstances it is easy to fail to identify poverty of any kind. It is likely to be hidden or not accepted simply because of the dominance of wealth in the area.

In Saddleworth, in collaboration with the Saddleworth Parish Council, a group has been formed looking at fuel poverty; the Chair of the

PPG is a member. All community associations in the area, health and other relevant professionals and Parish Councillors are being asked to assist in the identification of groups of vulnerable patients who could be helped considerably by accessing grants, loft installation etc. Short training sessions are being arranged looking at eligibility for grants, allowances etc.

Those identified are referred on to the Energy Saving Trust Advice Centre, Greater Manchester. After assessment those eligible are referred to appropriate agencies for assistance. Throughout the country 21 similar trusts exist to serve other areas.

To conclude: there are wide disparities in life expectancy between residents living in poor and affluent areas. In the wealthier there is an assumption all are rich. In my view this needs to be challenged. A PPG and practice can play a significant role in eradicating fuel poverty in all locations. This can prolong life. Surely a very real goal for all concerned with the health of the nation. Work on fuel poverty can also accelerate acceptance that a PPG is an integral part of any community.

Patient Partnership and Power— the challenge of patient participation in general practice.

The following is a synopsis of the Royal College of GPs Wessex Faculty 28th George Swift lecture delivered by Dr John Dracass, MBE FRCGP, previous Provost of Wessex Faculty, retired general practitioner and current NAPP Trustee., at Winchester Guildhall on 17 September 2009

We are now used to the concept of patient centred medicine and the importance of the patient view in the provision of health services, but it was not always so. For the first 25 years of the NHS, the voice of the patient was scarcely audible: Patients were passive recipients of care and general practice was largely outside democratic or managerial accountability². Since the 1970s there has been an increasing understanding of the contribution of patients to their own health care but progress has been slow.

Changing social trends

The need for increased dialogue with the public has been driven by key social trends over the past 30 years, including loss of deference to authority, the information explosion, consumerism and rising litigation; what the economist Chris Ham calls the breakdown of the implicit compact between the public and the profession, to which the profession's own scandals have contributed. A number of models have been proposed describing community involvement in public services, including Arnstein's ladder of public participation, which describes a hierarchy of participation from tokenism to citizen control.

The first patient participation groups (PPGs) in general practice were set up in the early 1970s. These groups represented the fruits of enthusiastic practitioners who believed that patients should be more involved in the running of their surgeries. My own practice set up a PPG in 1991. The development of PPGs went hand-in-hand with an increasing government agenda for patient involvement from "Working for Patients" in 1989 to the NHS Plan in 2000 and Real Involvement - Working with People to Improve Health Services, in 2008, which required PCTs, hospital trusts and local authorities to involve patients in planning health services.

Early aims of PPGs

The broad aims of patient participation groups were laid out in the early years. They are: to give patients a say in the running of the surgery; to improve communication between doctors and patients and provide feedback from patients; to provide a way of dealing with suggestions and complaints; to promote health education; to provide a base for voluntary community care and to campaign for better provision of health services locally. There is no set structure; each group determines its own activities and role, based on co-operation between patients and practice. It is not a forum for complaints nor is it a "doctor's fan club"

In 1980 the number of PPGs in the country was around 30. By the 1990s there were about 300 groups. Today, there are several thousand of varying style, composition and influence. The National Association for Patient Participation (NAPP) estimates that around 40% of practices in England now have a PPG. It is true that the majority of patient participation groups have been set up on the initiative of doctors rather than patients. Patients are reticent about giving their views but Anderson found that leaders with a shared commitment to public involvement can motivate others to be involved. With that stimulus local people can be drawn into the process and gain the confidence to be effective advocates for their community.

For many professionals there is a continued suspicion that patient participation risks the negative features of consumerism and a concern that a group will become a focus for complaint and criticism. My own survey of local GPs, however, showed that a half of respondents were from practices with a PPG and of those without, half again would support the formation of one. The majority of respondents thought that PPGs were valuable and only a small minority were totally negative.

Mature patient participation

If patient participation is to mature in general practice we will need to face the challenge of partnership with our public at a more effective level. That means moving towards the upper end of Arnstein's ladder. This will be challenging for GPs and patients alike. Patients do not find it easy to adopt a critical role and GPs do not find it easy to be challenged. Nevertheless it is my thesis that we have to grasp this nettle. To do this I believe we must move to a position where all practices have a PPG and we must encourage the development of existing PPGs to move up the ladder of participation. For both these aims, there must be adequate provision of resources, and I believe PCTs should now be offering financial and

administrative support to practices wishing to set up or develop a PPG. We need to undertake more research into the constitution and effectiveness of PPGs and patient participation in primary care must be integrated effectively into the wider participation agenda for the NHS as a whole. In addition, we must embed the concept of patient participation into general practice training. My survey found that GPs early in their career are less likely to be involved with patient participation groups and more likely to lack knowledge about them. Finally, we must take advantage of new developments such as Practice Federations and Practice Based Commissioning to ensure that the patient's voice is heard at the highest level.

General practice has been facing unprecedented media and government, pressure in recent years. Unless we embrace real patient participation in the development and planning of our services, we will risk losing a crucial ally for our profession, and credibility in an age when the voice of the consumer is increasingly taken for granted.

The Gosforth Valley Medical Practice PPG

The following article was received from Helen Jenkinson (Chair) Gosforth Valley Medical Practice PPG

The Gosforth Valley Medical Practice is based in Dronfield, North East Derbyshire. It is described as a suburban practice and has recently been accredited with the Quality Practice Award. The Patient Participation Group has been running since 2005, with a small group of loyal supporters from a practice list size of about 4000 patients. The group meets every 2 months in the evening at the practice premises for a couple of hours, and is attended by one GP partner and more recently by the new Practice Manager.

The group was originally convened by the

practice/GP Partner, and spent the first year learning more about the practice, NHS, the government health policy and how this all interrelated, and then started to explore its *raison d'être*.

After a few false starts, we would now define our functions as: -

Reflecting patient ideas, concerns and compliments to the practice.

Acting as a "sounding board" and providing patient comment for ideas and intended policy changes of the practice.

Organizing and staging open Health Education events for patients of all practices in the town.

The last function has now become the activity for which we are best known, and we've staged a number of successful evenings on health themes, such as bowel cancer screening; prostate problems; stress, anxiety and depression, flu and swine flu. In staging the above we have experienced the 'highs and lows' and with each event have gained a valuable learning experience that we have been able to utilize for the next. Detailed below is what we view as a :-)

Beginners Guide to staging a Health Event

- **Market research your topic:** Ensure there's real public interest and this isn't just the minority idea of one PPG member.
- **Costs:** Do research costs & budget for the event. The biggest costs are likely to be newspaper advertising, venue and speaker expenses. Costs can be minimised by seeking editorial coverage rather than newspaper advertising (but beware papers are under no obligation to publish what or when you want, so an advert is more reliable), making a shrewd choice of venue (e.g. church halls) and by recruiting local Consultants, Lead-Nurses or GPs on a voluntary basis – often travel expenses are negligible or waived.

- **Set the date:** Choose a date sufficiently in advance to allow for all the lead times involved; and one that misses other major local events, and falls on a mid-week.
- **Delegate the roles:** Use those with both enthusiasm and some experience. Good delegation involves setting expectations and ensuring adequate reporting of progress.
- **Choose the right venue:** Choose a venue that will accommodate the desired audience size, that has easy access and parking and on bus routes, that has the required facilities (e.g. PA, kitchen facilities, loop system).
- **Book early:** Secure the venue with a deposit early.
- **Recruit speakers early:** Leaving bookings late means early advertising cannot use speakers' names, and popular speakers are harder to secure as they may be unavailable. Once booked, confirm by email/letter, ensuring they know where the venue is (map plus address) and have details of access and start times.
- **Brief speakers:** Ensure speakers have a written brief defining exactly what it is you want them to address, to what size audience, in what time frame, etc. Ensure they know they are addressing the general public and not to use jargon or acronyms. Detail the presentation equipment available (e.g. Laptop/PowerPoint/data-projector).
- **Plan your advertising:** Use a selection of measures including laminated colour notices on public notice boards & shop windows, as well as in GP surgeries, library and other public buildings; advertisement in local magazines/newspapers or supply editorial copy and interesting photographs. Remember to take full account of lead-times for publication & distribution.
- **Set-up:** Arrange access to the venue early, and set the room up to best suit the meeting. Try to avoid straight rows of chairs, but create crescents/arcs. Take advice from, and make full use of, the caretaker.
- **Hosting:** If you've planned refreshments, ensure the kitchen is equipped to provide the basics and you've brought everything you might require. Have a doorman posted to welcome & direct your audience.
- **Front of house:** You will have planned the meeting carefully, so do start on time and stay on time. Welcome your audience, signpost emergency exits and toilets. Explain the purpose, format and content of the meeting, and introduce your speakers. Ensure they use PA (if available) and do hold them to both time and to explaining jargon/acronyms if they use them. Encourage speakers to repeat audience questions or do so yourself, so that the rest of the audience can hear what has been asked.
- **Closing:** Do finish on time for the sake of the audience, speakers and caretaker! Remember to thank your speakers and PPG support crew for all their hard work. Take the opportunity to formally or informally evaluate the meeting and to advertise future events.
- **Afterwards:** Ensure the venue is cleared on time, secured and keys returned if no caretaker is available. The following day, ensure posters are taken down, loaned equipment is returned, bills are paid and deposits reclaimed. If anyone has any questions or queries please contact us with your contact details.

*Our email address is
jenksmum@hotmail.com*

The Davenport House PPG: Reaching out to a younger audience

Many PPGs are familiar with the challenge of raising awareness of the Group among younger members of the practice, especially teenagers and parents of young children. Davenport House contacted NAPP to see if we could support their activities in this area.

Along with the rest of the PPG, Viviane Vayssieres, organised an event in Harpenden in September 2009 called Kidz on the Common, with literally no budget but a lot of good will and support from the surgery. Despite a rather windy and cold day, the event was well attended by young local Mothers.

The Doctors and the PPG felt that the exposure created and the networking with some of the agencies we had invited (children centres, Out Reach, Child Minder, NCT etc...) was of great value. So, they are now looking to hold it again in 2010, with a slightly different format, and bigger.

Their ideas include giving the children (500 +) a small branded gift, (the Nursery is already giving balloons) and producing PPG branded wrist bands, soft toys, T-shirts to create the exposure that is needed. The PPG wondered if NAPP is able to help..

NAPP has very limited resources but we are now hopeful that we can identify a small amount of funding to test out the success of this approach to raising the profile of the PPG among such a key section of the population. The PPG is also developing a new, interactive website and its newsletter regularly includes articles of interest to young families. To learn more, please email Viv at:

oldpalacelodge@paulerochelle.com

NAPP Chief Executive: Moving on after 7 years

After seven years involvement with NAPP, the last three as part-time Chief Executive, Graham Box has decided to step down with effect from June 2010. Commenting on his departure, Graham said:

"This was a very difficult decision for me since I have greatly enjoyed being part of the growth of PPGs over the past few years. I am convinced that PPGs represent an excellent model for successful patient and public involvement in primary health care..

In my view, they should be an integral and valued part of every GP surgery. In the coming months, I will continue promoting the model and working with partner organisations to ensure that PPGs have the support and recognition that they need and deserve.

I would like to thank the NAPP Board, our PPG members and all of the PCTs that I have worked with during my time as NAPP Chief Executive."

Cycling for PPGs and for NAPP

Our lead article on Page One described some of the campaign activity to *Put PPGs on the Map*.. This theme will be amplified by a sponsored cycle ride currently being planned by our Chief Executive, to coincide with his stepping down from that role (see above).

Over the course of a week, Graham is planning to travel through every Strategic Health Authority in England, ending his journey at the NAPP AGM in Rotherham on 5th June 2010. He will be able to highlight successful PPGs along the way and, we hope will attract media attention and sponsorship that will help both PPGs and NAPP.

This is a major undertaking and planning is at the early stages. Please let Graham know if you would like to help in any way, such as:

- Advising on how to maximise sponsorship
- Inviting Graham to visit your PPG or PCT
- Securing media interest

Any offers of help should be directed to:

graham@napp.org.uk

01628 820326

N.A.P.P. Annual Conference Saturday June 5th 2010

As previously reported, next year's Annual conference and AGM will be held in the Sheffield area on Saturday June 5th. The Title and underlining themes for the Conference are:-

Growing Patient Participation (Understanding—Challenging—Celebrating)

We have a provisional venue and speakers are currently being approached.

More details will follow in the next issue of the Newsletter.

N.A.P.P. Regional Conference February 2nd 2010

NAPP has arranged a regional conference at Taunton School on 2nd February 2010. This is aimed at practices and PPGs in the South West of England Strategic Health Authority. Workshops will be appropriate to three workstreams: Setting up a PPG, Developing a PPG and Supporting PPG Champions.

Please email audrey@napp.org.uk for more details and a booking form.

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