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Patient Participation: Moving On

Autumn 2003

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For a long time we have known the government's intention to "put the patient at the centre of the NHS". Implementing this simple concept has taken many forms and is evolving slowly. Faced with the enormous changes affecting primary care in the NHS it is little wonder that progress has been slow and priorities are affected by the pressure of achieving star ratings, on which funding and even jobs depend.

The N.A.P.P. project to develop patient participation through primary care trusts in England has had to take its place among the many initiatives in primary care. Some PCTs have acted faster than others, but overall we have not seen the results that we have hoped for. That is not to say that our message is not accepted and our help welcomed. The sixteen PCTs in the pilot phase of the project are all still active and some progress is being made. Many more PCTs are keen to get involved. Our preference would have been to evaluate the pilot activities fully before launching the materials and support more widely. It now seems likely that we will need to have a second phase of pilot activity to satisfy the growing demand. Support materials have also been developed in Wales. Future support materials will call on both these sources. The big question is how can we provide support on an appropriate scale.

The N.A.P.P. committee (comprising trustees, our President and Vice President) recently held an "away day" to consider the future of N.A.P.P. and review our objectives. It is clear that we can not be all things to all people. We looked at what we should be doing in the future. It includes:

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- Prioritising (Ensuring that the grass roots thinking is not lost)
- Raising our profile (and that of patient participation)
- Providing facilitation
- Developing and providing training (for members and sponsors)
- Facilitating excellence
- Accrediting success
- Getting patients involved in clinical aspects of their care
- Strengthening support to members
- Conducting research
- Expanding (Identifying, contacting and recruiting other PPGs)

Over the next few months we will be developing a business plan that will address these issues. It seems probable that this will require fundamental changes to how we operate. These changes will, in some cases, require the approval of our membership, which will be sought formally at an AGM or Extraordinary meeting. In the meantime we are keen to involve our membership in shaping our future.

If you would like to comment on the ideas in this article or if you might be willing to joining a working party exploring these ideas, please contact Roger Battye.

Changes on this scale will require us to acquire new skills and more effort generally. The opportunities are considerable, but so are the challenges. There are also risks. We learned recently that The College of Health, with whom we have collaborated in the past has gone into voluntary liquidation. We must learn from this sad event and make sure that any extension of our activity has a sound financial base.

Sir Denis Pereira Grey, who steered our AGM so skillfully, agreed to chair our away day. We are grateful for his presence, which enabled all of us to contribute fully. At the end of the day he was invited to become a patron of N.A.P.P. I am delighted to report that he accepted. He is committed to patient participation and is willing to use his not inconsiderable influence in our support.

Roger Battye, Chairman (N.A.P.P.)

FREE COMPUTER EQUIPMENT FOR PATIENT PARTICIPATION GROUPS

At the end of November all Community Health Councils will close their doors. The Commission for Patient and Public Involvement in health has decided not to take over any equipment in the CHC offices. ACHEW have informed N.A.P.P. that the equipment, including computers and peripherals, filing cabinets and other items will be scrapped if they are not transferred to voluntary groups in the community. If you are interested, please contact your local CHC office. Affiliated groups are asked to contact N.A.P.P. if they encounter any problem.

The Internet and N.A.P.P.

Following on from the article featured in the Summer Newsletter its worth noting that the N.A.P.P. website now features 38 links with other sites. Each link gives a brief resume of the organization concerned. Affiliates may wish to consider publicizing this feature to their respective patients - a good information resource!

If you navigate the NHS website you will discover an area titled 'Patients' Voice' at www.nhs.uk/patientsvoice

This area includes :-

- **The public's top 10**
- **NHS core principles**
- **Have your say**
- **How to complain**

Following a consultation exercise, the top 10 things the public wanted to see in the NHS plan were:

1. More and better paid staff - more doctors, more nurses, more therapists and scientists.
2. Reduced waiting times - reductions in waiting overall, for appointments and on trolleys and in casualty.
3. New ways of working - including 'bringing back matron'.
4. Care centred on patients - action on cancelled operations, more convenient services.
5. Higher quality of care - especially for cancer and heart disease.
6. Better facilities - more cleanliness, better food, getting the basics right.
7. Better conditions for NHS staff - reward and recognition for the work NHS staff do.
8. Better local services - improvements in local hospitals and surgeries.
9. Ending the postcode lottery - high quality treatment assured wherever people live.
10. More prevention - better help and information on healthy living

Therefore it's interesting to note with reference to point 9 the following article published on October 28th 2003 in The times by Oliver Wright—Health Correspondent (see next column)

'Action to stop postcode lottery for cancer drugs'

THE Government will announce plans today to eliminate "postcode prescribing" amid fears that thousands of patients are being denied life-saving cancer drugs because of where they live.

John Reid, the Health Secretary, will tell health authorities that he wants to know why some are still reluctant to prescribe new drugs even though they are recommended nationally.

He has put Mike Richards, the Government's cancer care director, in charge of the review, which is expected to report in the next few months. Mr Reid has promised that if funding is to blame, this will be addressed by the Government. The cancer review is likely to be followed by similar exercises for other types of illness.

A survey found that only a third of women who could benefit from a new breast cancer drug had access to it. The charity CancerBACUP said that 61 per cent of women in the South West had access to the drug Herceptin, but only 14 per cent of women in the Midlands could get it. Overall, the charity calculated that more than 1,000 women were unable to get it.

That was despite a ruling by the National Institute of Clinical Excellence (NICE) that the drug should be made available to all women with advanced breast cancer. Over the past few years 16 new drugs have been recommended by NICE for the treatment of different cancers. Most are still not believed to be available equally nationwide.

The Government does not keep data of prescriptions by primary care trusts, so Dr Richards intends to travel to cancer treatment centres to establish the situation.

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A Department of Health source said: "Mr Reid is committed to ending the postcode lottery and ensuring that patients who need vital drugs are not denied them on grounds of funding. The differences we are seeing in terms of the take-up of these new drugs are simply not acceptable. Patients should be given the drugs they need and it should not matter where they live." The source added that Dr Richards wanted to know whether there were clinical reasons why some areas appeared to have a low uptake or whether the reason was entirely financial.

The move has been welcomed by CancerBACUP and Cancer Research UK, both of which highlighted the issue. Richard Sullivan, head of clinical programmes at Cancer Research UK, said 'People are not getting the drugs they need. This appears to be a sign that the Government is starting to address this issue.

Joanne Rule, chief executive of Cancer BACUP, said: "Mike Richards is extremely well respected and we are very pleased that he is going to be carrying out this review.

Hopefully somebody is listening to patients, because as the article points out this so called 'post code lottery' is not confined to cancer sufferers.

Also on the nhs website the NHS Magazine 'Primary Care' may be accessed. The following article is reproduced from this website on 29/10/03

Faster Surgery at NHS Treatment Centres

About 250,000 NHS patients will get faster access to surgery at new NHS Treatment Centres being set up across the health service.

Minor operations will be carried out in new buildings or refurbished NHS hospitals covering 26 areas.

The units—which were known as diagnostic and treatment centres—will be located across England and will offer high quality, safe, pre-booked surgery and diagnosis facilities, particularly in those specialities with the longest waiting times for patients including orthopaedics and ophthalmology . Around £2 billion is being spent over the next five years and all the centres will be up and running by 2005.

Of the programme's planned 250,000 operations, 135,000 will be extra while 115,000 will be transferred from existing NHS resources.

A shortlist of the Government's preferred private sector companies bidding to run the centres has been announced.

Patients Association policy director Simon Williams said: "Any initiative that helps to reduce waiting times and provide a better service for patients must be encouraged as a positive step forward in improving and modernising the NHS in the 21st century."

Press Summaries—News in Brief

Violence against NHS staff

Nearly one in ten doctors is physically assaulted by patients or their relatives each year, a survey by the BMA has found. One in three doctors had experienced some kind of physical or verbal violence in the last year, and those most likely to be assaulted worked in A&E departments or in psychiatric services, but GPs also faced growing levels of violence. In response John Reid promised that violent patients and relatives would be prosecuted for attacks on NHS staff.

The Times, Daily Telegraph, The Independent, The Guardian, Daily Express, Daily Mail, The Sun, Evening Standard

NHS fast-track surgeries

Four NHS fast-track surgery centres have banded together to market potentially thousands of operations a year to NHS patients. Central Middlesex Hospital has joined with units at Kidderminster, Weston-super-Mare and Ravenscourt Park to form a new organisation, NHS Elect, to offer operations to every health authority and trust in the country at NHS rates. Meanwhile, the Daily Mail reports that surgeons at Southport and Ormskirk Hospital resisted referring hundreds of patients to NHS DTCs for their hip operations because they wanted to perform the operations for the patients privately.

Financial Times, The Mirror, Daily Mail

GP vacancies

The number of vacant GP posts has risen by almost one third in the past year and is at the highest vacancy rate ever experienced, the BMA has warned. There are now 3,435 vacant GP posts compared with 2,630 last year, and the number of applications for each post in the same period fell from 4.4 to 3.3. Lib Dem health spokesman Paul Burstow said "patients are facing enormous difficulties finding a GP. Quite simply, the crisis is heading towards a meltdown."

Daily Telegraph, Daily Mail, The Times

NHS recruitment

The NHS is poaching top specialists from the Indian subcontinent, according to a report in the BMJ. Vikram Patel, senior lecturer at the London School of Hygiene and Tropical Medicine, warned that "the NHS has launched a scheme to recruit senior psychiatrists from India and other developing countries."

The Independent

CHAI

The Financial Times Diary section suggests that Wendy Thompson will be appointed as the new chief executive of CHAI. She has previously been working for the Office for Public Sector Reform in the Cabinet Office, for the Audit Commission and as chief executive of Newham Borough Council.

Financial Times

Foundation trusts

Howard Davies, director of the London School of Economics, writing in the Financial Times criticising the government's proposals of allowing foundation trusts to appoint their own auditors as "inconsistent with the principles of public sector audit." Meanwhile, Fiona Campbell of the Democratic Health Network writes to The Guardian and the Financial Times warning that "the governance arrangements for foundation trusts are going to be more complex than existing NHS trust boards" and that "foundations would blur the distinctions between the NHS and private medicine."

Financial Times, The Guardian

Alternative medicine

Herbal remedies and other alternative medicines should be made available on the NHS, DoH director of patient experience and public involvement Harry Caton has said. Despite a lack of scientific support, Mr Caton recommended that these remedies should be made available to patients if they believed they were beneficial, as part of the Government's choice programme.

Sunday Telegraph

Long term care for the elderly

Thousands of families are being cheated out of millions of pounds by local health authorities deliberately ignoring a series of legal rulings on long-term care costs, the Sunday Express Financial supplement reports. Figures researched by the Liberal Democrats show that the bill for compensation claims from victims' families could total £557m.

Sunday Express

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A private claims handling firm, according to The Guardian. The Barts and the London NHS trust, allows a private claims handling firm to advise victims in its A&E unit, and the Royal Surrey County Hospital writes to patients within 48 hours encouraging them to make a personal injury claim. Critics have called the move "an alarming new development in the compensation culture."

The Guardian

CAN YOU MAKE TIME FOR HEALTH?

A campaign has been launched to recruit members of the public to become champions for health. The 'Make Time for Health' campaign, which is being run by the Commission for Patient and Public Involvement in Health (CPPIH), aims to recruit members for almost 600 locally-based Patient and Public Involvement (PPI) Forums, one for every Primary Care Trust (PCT) and NHS Trust in England.

The campaign is designed to encourage participation from patients and the general public. Anyone can apply to be a member of PPI Forum, irrespective of ethnic origin, gender, sexual orientation, age, disability or religion.

PPI Forum members will:

- encourage others to get involved
- find out what people really think about health locally
- independently watch over the quality of local healthcare
- shape decisions which impact on our health
- influence local and national decisions as part of a growing network for public involvement
- be a force for fairness and change

Telephone lines for PPI Forum membership enquiries are open on 0845 120 7115. Membership registration can also be made online at www.maketimeforhealth.org

Sharon Grant, Chair of the CPPIH said:

"The arrival of the Forums presents a unique opportunity to put the public at the centre of health, and to reform the whole culture of health care. We're standing by to receive large numbers of applications from all sections of the community who want to be Forum members."

The Commission has also put in place administrative offices (Local Network Providers) who will work with CPPIH's nine regional centres in providing all necessary support, training and development to PPI Forum members.

The Commission's main objective is to empower patients and the public by integrating them into the decision making process on health and healthcare delivery. CPPIH and its nationwide PPI Forums will succeed Community Health Councils (CHCs) by 1 December when CHCs cease to exist

Newsletter Mini Survey

Thanks to all who returned the postcard for the recent survey.

68 responses were received. The main findings are that the newsletter reaches a considerable majority within a week of posting. Nearly all recipients were the main contact and member of the PPG and were also a patient of the respective practice. Over 90% displayed the newsletter in the waiting room in order to make it available to patients.

The final question however showed massive differences. The responses on how many people actually read the newsletter ranged from 0 to 8000!!

The reason for this wide range owed mostly to the nature of the question which in hindsight was extremely subjective.

However thanks to all who took the time and trouble to complete the survey. The results will hopefully be featured on the N.A.P.P. website in the near future.

Competition Results

Apologies to those who tried to enter the 'Who am I? summer competition and did not have the necessary address. This was due to the editor's oversight. Consequently only two responses were received and the winner who correctly identified **Albert Camus** as being the correct solution were **The Friends of Testvale Surgery Southampton**. A year's free membership is their prize.

See page 8 for this issue's competition. The address for posting your solutions is now featured there.

So what is happening with your PPG? Why not share some of the interesting events—features- etc with other members of N.A.P.P. Either email or write to the editor. Its your newsletter so if you can spare the time to let us know what your group is engaged in we'll be only too pleased to include it in the next issue.

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Competition No.2) 'Who am I?'

Send your solution in an envelope marked 'Who am I?' Autumn 2003
To the Editor—Danny Daniels 21 Croffta, Dinas Powys, CF64 4UN. Entries to be received by December 31st.

- I was born Isabella Mayson in the 19th century
- I was the eldest child in an extended family of 21 children
- I attended finishing school in Heidleberg
- I lived for much of my life in Surrey
- I married my husband Sam in 1856
- I died when I was only 29
- I am most famous for a certain book which was first published in 1861

Who am I?

*The competition is open to **currently registered affiliates only**. **Trustees are not eligible**. First correct solution opened will win a one year's free membership for their group. Editors decision final. Winner to be announced in next issue of Newsletter.*

And Finally

1. The plea from our Chairman, Roger Battye, in this issue's leader is for contributions from affiliates in the form of comments or to serve on working parties. We need to shape N.A.P.P. for the 21st century. For a number of justified reasons we cannot continue as we have in the past and need to re-focus. As we emerge with a strategy we will keep affiliates informed of progress.

2. This newsletter contains a number of patient and health related articles re-printed from either the press or from the internet. Whilst it is seen as a responsible function of the editorial process we suffer from a dearth of contributions from members. If you have any article which you feel may be of interest to other members please do not hesitate to pass it on. The editors address details can be found on page 7.