



# N.A.P.P.

## Newsletter

Patron. The Rt.Hon. The Baroness Chalker of Wallasey.

Registered Charity no 292157

Contact N.A.P.P. at PO BOX 999, NUNEATON, WARMS, CV11 5ZD or [www.napp.org.uk](http://www.napp.org.uk)

### Winter 2003

# N.A.P.P. PCT SUPPORT PROJECT (England)

### In This issue:-

	Page No
Researchers need people like you.	2
N.A.P.P. response	2/3
Patient libraries	3
New Book Review	3
Activity Survey	3/4
N.A.P.P. website	4
Patients' forums	4
NICE Newsletter	4
Letters to the editor	4/5
Pharmacies & Competition	5
Positive Feedback	5
Caring for the Carers	5/6
N.A.P.P. executive	6
Spotlight on Wales	7
Health Information & Fun Day	8
And Finally	8

Is there anything of interest that you would like to share with other

groups? Send your article Or letter to the Editor

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This project is nearing completion, although we have applied for a further year of Section 64 funding to cover implementation. We will provide a resource pack for PCTs to enable them to encourage the formation of PPGs within their area. Our project manager Graham Box has contacted all 350 PCTs in England. The responses have been quite encouraging.

Initially we will work with about 15 PCTs as pilot projects, to evaluate the materials and test the ability of N.A.P.P. to support PCTs. We aim to involve members of active PPGs to assist with this. The package will subsequently be made available to all PCTs.

The work has already generated some spin-offs that will help N.A.P.P. in the future. We have developed a training programme for our volunteers. This is designed for local representatives so that they can contribute fully to the development of patient participation. It will also help regional co-ordinators and trustees to get up to speed and become familiar with the role of N.A.P.P. and its relationship with the NHS.

Our efforts are directed to helping the PCTs to understand what is special about PPGs and to encourage them to replicate the many good examples already in existence. They are coming to realise that this is a slow process and that firm foundations of trust and shared interests are fundamental to success.

Our project is very much in line with the guidelines for PCTs in involving the public. This is no great surprise as N.A.P.P. is involved with the Significant Issues Group of NatPaCT, which is the National Primary and Care Trust support organisation. N.A.P.P. is contributing to the definition of competences that PCTs should develop in order to meet their obligations for public involvement. These will include encouraging the introduction of patient participation at surgery level.

Further information about NatPaCT can be found on their website at [www.natpact.nhs.uk](http://www.natpact.nhs.uk).

## Researchers need people like you

Consumers (patients, service users, carers and others) have always been involved in NHS research. Their role has usually been that of “subject” for a particular research project. Now they are beginning to play a more active part in some or all aspects of the research process.

They now work in partnership with researchers and health professionals to decide the kind of research that should take place. They also help to commission, carry out, monitor and evaluate and publicise (disseminate) research.

Consumers bring a very special dimension to this process by ensuring that the research is relevant and helpful. They can also bring their own experience and perspectives to ensure that research findings help to improve services.

Some groups of consumers have commissioned and carried out their own research. You do not have to be a genius to get involved with research. No special qualifications are needed, though you may need to develop some skills to help you. It is not something that everyone will want to do. But it is important that you can make an informed choice about whether you want to get involved.

Organisations like the Alzheimers Society ([www.alzheimers.co.uk](http://www.alzheimers.co.uk)) involve consumers in almost every stage of the research process. The Society has found that this greatly improves the way in which research projects are commissioned and monitored. Consumers have also derived great benefits from their participation. Do visit their web site to find out more.

Consumers in NHS Research is a group that advises the Director of R&D (Research and Development) in the Department of Health on ways to involve consumers in research in the areas of health, public health and social care. The Consumers in NHS Research Support Unit builds links with and provides information, advice and support to both consumers and researchers. We also give talks and workshops and organise conferences on consumer

involvement in research.

Our objectives are to;

- ◆ Build partnerships
- ◆ Promote consumer involvement in research
- ◆ Encourage consumers to become more involved in R&D Monitor and evaluate the effects of their involvement

We have produced a number of publications and a quarterly newsletter to inform both researchers and consumers. All of these can be ordered free from us or downloaded from our website at [www.conres.co.uk](http://www.conres.co.uk). If you would like to be added to our mailing list to receive copies of the newsletter or to find out more about what we do, please contact us at;

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**Paul Jones**  
**Liaison Worker at Consumers in NHS**  
**Research Support Unit**

## Consumers in NHS Research (A response from N.A.P.P.)

It came as something of a surprise that there is quite a lot of research conducted in primary care. It seems it is not the sole province of pharmaceutical companies and teaching hospitals. The public are invited to participate in the research. This is not limited to patients involved in trials. Members of the public are needed to help to design the trials and even to prioritise the topics researched.

N.A.P.P. is working with the Consumers in NHS Research Unit to help find volunteers to work with researchers on projects around the country

As news of projects is received we propose to contact groups in the area to alert them to what is going on. We hope that some of your

members will agree to take part in the work, which can benefit us all.

A general invitation is offered for you to become readers to assess the suitability of information for the general public. Payment is made for this work.

A booklet "Getting involved in research – A guide for consumers" is available from: Consumers in NHS Research Support Unit (Address—Website and email details on page 2)

A link will also be found on the N.A.P.P. website

## Patient Libraries

To help new groups who decide to start a patient library, N.A.P.P. is developing a list of books, leaflets video and audio cassettes. The list will suggest items that could form the basis of an initial library and those that could be added later as further funds are available. Items will be categorized and the opinions of the relevant specialist patient support organizations sought.

We intend to review this list regularly to ensure that new items are added when they become available and those that are dated are removed.

Any group proposing to operate a patient library is advised to consult the practice before including any item to ensure that the information it contains supports the practice policy on treatments and patient information. From time to time new items will be reviewed in this newsletter. If we are able to negotiate preferential rates for PPG purchasers we will do so.

All groups operating patient libraries are invited to suggest additional items. All suggestions will be checked with the relevant organizations before inclusion.

The list will be made available only to affiliated groups. When the members section of our website is introduced the information will be included there, enabling groups to access the latest information.

## New Book Review

*'Man 120,000BC to present day' -*

**A Haynes Owners Workshop Manual.  
ISBN 1 85960 931 7**

No, it isn't a spoof and yes, it is a genuine Haynes workshop manual!

This novel approach is designed to overcome the reluctance of men to involve themselves in their own health. The book follows the usual workshop manual content with chapters covering subjects like **Engine** (heart and lungs) **Cooling system** (circulation). I will leave the contents of **Fuel and exhaust** to your imagination.

Although the approach is light-hearted, the information is factual and readable. It covers what the various bits do and of course includes a **Fault finding** section.

This is probably the best workshop manual a woman could buy for the man in her life and reading it could be one of the best ways to repay her.

The author, Dr Ian Banks is the president of the Men's Health Forum and is also the author of the NHS Direct self-help guide.

Available from Halfords, Waterstones and other booksellers or £12.99 on line from [www.haynes.co.uk](http://www.haynes.co.uk)

N.A.P.P. is trying to negotiate a discount for affiliates.

## Activity Survey

The 2003 survey is distributed with this newsletter. It repeats most of the questions in the last survey, so that we can assess what has changed in the last three years. It also includes a new section on the effectiveness of patient participation on the NHS. We hope that all groups will compete and return the survey by the end of April. This will give us time to analyse the results and present them at our conference in June.

If your group can not meet that deadline, we

would still like to hear from you and your results will be added when we get them. The updated results will be available on our website or on request for those who do not have web access.

### **N.A.P.P. Website**

Our website is generating a number of leads from practices and primary care organizations interested in starting a PPG. It is also becoming a reference site for people interested in what is going on generally in the public involvement world. The number and diversity of links to other organizations is growing. We are being asked to publicize more events and consultations. This all seems like good news and we are pleased to contribute to the sharing of information. What we don't have and we would like to have is comments from our members about the information.

We plan to use the website as a way of giving you up-to-date information in a way that paper can never do. Before we invest time and money in doing this we would like to hear what YOU want to see!

### **Patients' Forums**

At the time of writing we are not much further forward. The Commission for Patient and Public Involvement in Health appointed its directors on January 1<sup>st</sup>. It seems that the forums may not be operational before Community Health Councils are abolished in September 2003. It seems that money to fund the forums

will not be available until the CHC funding has ceased. Strategic Health Authorities are taking some action to prepare for the changes. These include asking PCTs to compile a list of members of the public interested in becoming members of forums. They have also been asked to identify premises that might be available for forum staff and meetings.

These actions should not be taken as an indication that PCTs will challenge the independence of forums, nor restrict any who volunteer to be forum members. Forums will be independent statutory bodies and membership will be controlled by the CPPIH, which is itself an independent statutory body.

The name Patients' Forum is not considered to be appropriate, but there is no clear preference for any other name. Maybe we will see a public relations firm commissioned to solve this problem for many times the amount of N.A.P.P.'s annual budget!

Whatever the final answer it is likely to include the locality name in the title.

### **NICE Newsletter**

The National Institute for Clinical Excellence (NICE) has developed a monthly newsletter for distribution via email to give those working with NICE a regular update about our work. The e-newsletter was launched in November 2002. We hope you will find the newsletter of interest.

About the e-newsletter:

The newsletter is intended to give those working in the NHS, healthcare professionals and patients a regular update on the work of NICE.

Each month it will include a round-up of guidance and consultation papers that have been published, together with information about forthcoming events and a list of guidance the Institute expects to launch next month.

How do you subscribe to receive a copy of the e-newsletter?

Visit the NICE website (see below) to register your details. Select E-newsletter, pick an issue, scroll to the end and click where indicated.

If you are currently registered to receive email alerts from the NICE website you will receive the newsletter automatically.

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### **Letters to the Editor**

N.A.P.P. is pleased to publish letters and articles from affiliates and interested parties. However we would remind contributors that N.A.P.P. is an apolitical organisation and therefore we cannot endorse opinions

offered. We do however feel that the N.A.P.P. Newsletter is the correct vehicle for airing issues, raising awareness and giving PPGs the right to respond.

## Pharmacies and Competition

*From: Jack Saltman, Chairman of The Friends of Capelfield Surgery*

This is an urgent appeal to help save your local community pharmacy. As a result of a report from the Office of Fair Trading, they are facing extinction in the same way many other local shops have gone.

At the moment, pharmacies can only dispense NHS prescriptions if they have a license from the local NHS Trust. These were limited to prevent a wholesale takeover of community pharmacies by the big chains and supermarkets.

Now the OFT is recommending that this control is ended. By undercutting local community pharmacies and by running shift work, the supermarkets will spell the death of your local chemist. For the sake of saving a small amount of Government money and a few pennies on the shopping bill the OFT will make it economically impossible for many community pharmacies to survive.

'Consult your local pharmacist' is the current buzz expression. This wonderful community resource where top class professional advice is on tap will just not be there to be consulted. A short term gain – for a big long-term loss. And who will

suffer the most? It will be the older patients and the young mums, big on children but small on transport!

If you want to help save your local community pharmacist write with your point of view to Peter Dunlevy, Community Pharmacy Policy Manager, Pharmacy and Prescription Branch, Dept. of Health, 155 Richmond House, 79 Whitehall, London SW1A 2NS

...AND TO YOUR LOCAL MP

## Positive Feedback

*Graham Fisher of the Putnoe Medical Practice PPG has recently written to our Chair Roger Battye with the following comments:-*

"I'm writing to say how encouraged we are to now be linked through N.A.P.P. with other Patient Participants to :- (a) to know that we aren't alone and (b) that there's such a wealth of experience we may learn from and draw upon.

The reason for joining N.A.P.P. was really because our current PPG set up, had reached a point of saying 'where are we going' now after functioning for 6 years and not involving many patients? Now both through yourselves (learning of you through the Royal College of G.Ps') and through what might seem chance encounters - we are seeing there's a whole new field of opportunity to enable our patients to become involved and themselves benefit from this in a number of ways.

So this is a 'heartfelt thank you. When we've learn't more by our own experience, perhaps we'll be in a position to make some more constructive comments to help improve further your 'Information Pack' - give us two years!

## Caring for the Carers A CARERS LEAFLET

*We are pleased to publish the following article received from the*

*King Edward Road Patients' Support Group —  
Christchurch Medical Centre Northampton*

At King Edward Road Surgery, Northampton, we have an excellent Patient Participation Group. There is a small steering group of patients which meets monthly with the practice manager. Apart from many varied activities where we help the surgery, we organise four educational evenings during the year for all patients and have had a variety of extremely interesting speakers.

Each year a project has developed and last year was no exception. At our steering group meeting we had been talking about how carers could be identified within a practice. This discussion went back to our GP's and it was their suggestion that they would support us if we could produce some information that they could give out to carers.

An advertisement was placed in Contact, which is our quarterly newsletter produced by a member of the

*(Continued on page 6)*

*(Continued from page 5)*

participation group, asking for carers to get in touch. A small group of carers met together at an informal coffee morning to discuss our idea. There was some concern that this might have turned into a complaints session but nothing could have been further from the truth. They were all delighted with their treatment from the practice but all felt they would have benefited with more information about services that were available in the town. There is of course a wealth of information in many different formats, but a busy GP has little time to wade through it all and pick out the most relevant bit for one particular need.

After the informal coffee morning we had a formal meeting and invited, in addition to carers, four representatives of professional groups that had produced their own leaflets and worked with carers. This worked extremely well. We looked at all the categories of caring that a patient might experience and made sure each was covered by a local organisation that could, if needed, signpost a carer to an appropriate group.

The carers blossomed. One lady, who had just become a carer, became the secretary; I designed the leaflet and in fact did all the donkeywork. She is now a member of the steering group and is becoming increasingly involved with local NHS issues.

Other carers wrote articles for Contact about their caring situation. All of them were

deeply committed to the work being undertaken.

During the eight months from the initial idea to the official launch the Patient Steering Group and the practice were kept very much informed. It is so important to keep everyone "on board" and involved in decision-making.

The initial layout and contact with all the organisations that we were going to include took some time but when this was completed, the draft format of the leaflet was handed over to the Primary Care Trust for their graphic designer to complete the finishing touches. When we had all agreed the final version the leaflet was sent to the publishers.

It was decided that instead of an educational evening in November we would have a Carers Coffee Morning at the practice, for carers and any patients who were interested, where we could officially hand over the leaflet to the partners.

Various voluntary agencies were invited to be on hand to answer any queries that might arise about caring. A display for carers was set up in the lobby of the building and this remained for a week. The leaflet was formally handed over to the practice at the end of the coffee morning.

The leaflet is now being widely used by all members of the practice and indeed other surgeries and NHS organisations are wanting to adapt it for themselves.

We feel this is an excellent example of a practice working together with a patient group for the benefit of patients.

**N.A.P.P.**  
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**(All except the President and Vice-President are trustees)**

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## Improving Health in Wales—A public information booklet

The Welsh Assembly Government published the 'Health and Social Care Guide for Wales' in October 2002.

The publication is in Welsh and English and is packed with clear information and advice for potential and existing patients. Distribution however is suspect, Your editor was only made aware of its existence in February and initial enquiries would suggest that only limited numbers of copies are being sent to practices.

PPG's in Wales are therefore urged to ensure that they obtain sufficient copies for their respective practices.

Contact details:-

Performance Quality and Regulation

NHS Wales Department

Welsh Assembly Government

Cathays Park

Cardiff, CF10 3NQ

The guide is also available online at :-

[www.wales.nhs.uk/hscguide](http://www.wales.nhs.uk/hscguide)

## Funky Dragon- new Welsh Assembly web site for Children and Young People

This site is of interest to young people. However I urge you all to check it out. It's designed to assist young people a means of expressing themselves and becoming active citizens. Go to:-

[www.funkydragon.org](http://www.funkydragon.org)

## New Hospital for Neath - Port Talbot

A new hospital opened at the end of November 2002 for the people of Neath and Port Talbot. The hospital has 270 beds and will re-provide and further develop the services which were based at the Neath and Port Talbot General Hospitals respectively

The services include :-

- ◆ Medical admissions facility, with a total of 121 medical beds
- ◆ Coronary care and high dependency facilities
- ◆ 56 elective surgery beds
- ◆ High specification operating theatres and day surgery unit
- ◆ 24 hour local accident services
- ◆ Consultant and midwife led maternity services
- ◆ Childrens assessment unit
- ◆ Range of rehabilitation services, including elderly and day hospital and pre-discharge ward
- ◆ Full range of outpatient clinics

### ***Change in provision—A Patient's Perspective***

Following years of uncertainty over the proposed new Hospital for Neath—Port Talbot (West Glamorgan ); it has suddenly materialised on a site at Baglan Moors. Patients were transferred from the old hospital at Neath on November 30th 2002. (St Andrew's Day) - Why not March 1st?? The patients were taken in a fleet of ambulances to the new hospital and the operation was successfully completed in a day.

For years the communities were left wondering where the new hospital would be sited, would there be enough money and would it be large enough to accommodate and provide improved services for the whole of Neath and Port Talbot.

A lot of ground work went into the construction, planning and operational services and only time will tell if it serves its purpose.

It will be sad to see the old hospital demolished—it has served its patients well. No doubt the staff who looked after the patients will have their memories.

However I wish the new facilities well and sincerely hope that patients within the area view the changes in provision as both an improvement and beneficial to the community.

***Hazel Ackery Vice President of N.A.P.P. and a resident of the Neath - Port Talbot area. And a 'grateful patient'***

## Health Information and Fun Day

*The Family Practice Support Group in Dinas Powys South Wales organised the above event in the autumn of last year.*

The event was organised for two main reasons. Firstly because we are a relatively new PPG and we saw this as a means for awareness raising. Secondly our constitution's aims contain the delivery of Health Information and Education as its main platform. Obviously planning and strategy took up a considerable amount of time. All representatives of the primary sector were invited plus alternative therapies. We

make a conscious decision to appeal to the younger element and secured the services of the South Wales Fire Service who supplied two tenders plus a manned stand. Children had a great deal of fun with the interactive bodyworks exhibits hired from Techniquet Cardiff. The local leisure centre manned a stand and operated an electronic rowing machine for volunteers. Face Painting was offered for the juniors whilst many of the visitors availed themselves of the services of a reflexologist. Slimming World, Neighbourhood Watch, Community Police, Health Watch, Local Health Group and the Community Health Council were all represented. The event was held on a Saturday between 10.30 and 3.00 and a total 175 visitors

attended. The Practice stand offered health checks in the form of diabetes diagnostic testing and blood pressure checks. A total of 100 patients availed themselves of this service. Four cases gave cause for concern and these individuals were referred. In all we thought the day was a success and are currently evaluating our efforts with a view to making the event an annual feature of the community. Publicity including press releases, distribution of posters and leaflets to all local public venues and schools were a vital contribution to the outcomes. The contributions from all members of our group was equally important. In conclusion—a lot of hard work but well worth it.

## AND — Finally

A big thank you to all contributors to this issue. Please send in interesting articles or alternatively letters concerning issues which you would like aired. The Newsletter is also a good medium for networking and sharing good practice.

I have, to date, received a nil response concerning whether you would like to see cartoons, crosswords etc. included within this publication. I personally feel that the written word can be boring in isolation and that the Newsletter needs 'breaking up' to a certain extent. Please let me know your views.

In the next edition (Spring 2003) we will be publishing details of our Annual Conference to be held on Saturday June 7th at the Barnsley and District General Hospital in South Yorkshire. Our sub committee working on the planning for this event are hoping to make it a memorable 25th Birthday Conference (Yes the National Association for Patient Participation is a quarter of a century old!!)

**Is there anything of interest that you would like to share with other groups? Send your article or letter to the Editor N.A.P.P. Danny Daniels 21 Croffta Dinas Powys CF64 4UN or email [danny.daniels@napp.org.uk](mailto:danny.daniels@napp.org.uk)**