

Best Practice in Patient Participation in Primary Care

**Final report on a three year project
funded by the Department of
Health:**

2004-2007



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Best Practice in Patient Participation in Primary Care

Introduction

This best practice project, funded under Section 64, required that we identify and disseminate examples of good practice, where patients or patient organisations are successful, or have been successful, in influencing the NHS. The research has a particular focus on primary care and the Department of Health requested that we take a special interest in the ability of minority groups to exert influence.

The work began in July 2004 and this report describes activities and progress during the project's three year duration. It begins with an Executive Summary of achievements to date before presenting a more detailed account of the work that has been undertaken.

Executive Summary

The key achievements of the project are summarised below:

- a) Identification of 66 examples of good practice from Primary Care Trusts, PPI Forums, Patient Participation Groups and other settings with a particular focus on minority involvement
- b) Updating of our video describing the work of seven Patient Participation Groups from across the country
http://www.youtube.com/watch?v=t8tNBk96C_4
- c) Publication and distribution of *Moving Beyond Them And Us*, a case study document capturing the experiences of more than thirty Patient Participation Groups
- d) Commissioned study from the Picker Institute to examine the involvement of black and minority ethnic groups in the NHS
- e) Publication and distribution of *Minority Matters* which pulled together our learning across the broad range of minority groups (ie not just black and minority ethnic groups) that we have covered during this project.
- f) Completion of a major survey of patient participation in primary care covering 3600 practices and every English Primary Care Trust, generating more than eleven hundred responses

- g) Successful completion of a project supporting 25 Patient Participation Groups as pilot sites to improve their, and our, effectiveness, including a miniconference in Eton to share the learning
- h) Drafting of training materials (in partnership with Oldham and Preston Primary Care Trusts) incorporating video interviews with patients who are working to influence the NHS, to support the lessons from the best practice project
- i) Initiation of a monthly ebulletin describing key issues relating to patient and public involvement in primary care
- j) Redesign of N.A.P.P. website to host all of these materials and more besides, such as Ten Minute Guides in key policy areas and key documents from other organisations
- k) Three regional conferences (in Derby, Coventry and Exeter) were delivered, in partnership with Connecting for Health where half the day was devoted to best practice in patient participation in primary care
- l) Linking with a doctoral student at Birmingham University who has undertaken a comprehensive literature review (not yet published) on the work of patient participation groups in primary care
- m) Presentation of findings at a wide range of conferences and meetings throughout England including N.A.P.P.'s annual conferences

Where appropriate these materials can be found at www.napp.org.uk

Conclusions

C. The best practice project has been a great opportunity for the National Association for Patient Participation to acquire a deeper understanding of current successes and challenges relating to patient and public involvement. The project has identified a clear challenge for us as the rapid recent growth in Patient Participation Groups represents a great opportunity. There is a clear and important role for N.A.P.P. to support those Groups to ensure that the genuine voices of patients are heard and that the very real contribution that they can make to improving health is recognised.

New financial and manpower resources will be required to meet this challenge and the Trustees have identified these areas as major priorities. But we draw strength from the many examples of excellent work that we have encountered during this project, and remain committed to the remark of Joan Mant, a former vice-president of N.A.P.P. that "patients have much more to offer their doctors than their illnesses."

Graham Box
Chief Executive
N.A.P.P.

Danny Daniels
Chairman
N.A.P.P.

Acknowledgements

We greatly appreciate the financial support from the Department of Health that has allowed us to undertake this major piece of work.

We are grateful for the engagement and support of so many individuals and organisations who have given their time to share their experiences with us. In particular, we thank Dr Sandy Herron-Marx, Paul Bagley, Carol Fare, Rosie Kingham, Jill Higgins and John Barlow for their different but very important contributions.

We continue to be hugely impressed by the achievements of our own affiliates who continue to work as volunteers to improve the health and well-being of their local communities. We have chosen not to name them here but our thanks remain heart-felt.

We would like to thank the N.A.P.P. Trustees and Bob Bryant for their interest and advice throughout this project and, in particular, Roger Battye who got the ball rolling before his retirement as N.A.P.P. Chief Executive and Edith Todd who, as N.A.P.P. Treasurer secured the funding.

We continue to be amazed by the efficiency and good humour with which Audrey Hoggard, our Honorary Secretary, takes on every task – her contribution to this project has been immense.

Best Practice in Patient Participation in Primary Care

1. Introduction

Funded by the Department of Health, this best practice project set out to identify and disseminate examples of good practice, where patients or patient organisations are successful, or have been successful, in influencing the NHS. The research has a particular focus on primary care and the Department of Health requested that we take a special interest in the ability of minority groups to exert influence.

The work began in July 2004 and this report describes activities and progress during the project's three year duration. In general, the supporting documents can be found on our website at www.napp.org.uk

2. Good practice examples

These were identified throughout the project with the majority of the research carried out by Trevor Gay and Mohammed Lais, complemented by the Picker Institute's research into the involvement of black and minority ethnic communities. The case studies were drawn from Primary Care Trusts, PPI Forums, Patient Participation Groups and other organisations. Each example was presented on a single side of A4 with appropriate contact details (though some of these will have changed subsequently).

We scaled down work in this area once the NHS Centre for Involvement was commissioned (see www.nhscentreforinvolvement.nhs.uk). With its larger budget and networks, the Centre will be able to identify and disseminate good practice on a far grander scale than we could manage.

As part of this project, we have updated our DVD of seven Patient Participation Groups from across the country and have uploaded this onto YouTube. As a result it is easily viewed (though there is a drop in the visual and sound quality) at http://www.youtube.com/watch?v=t8tNBk96C_4

3. Moving Beyond Them And Us

Although Patient Participation Groups have been active for thirty-five years, there are still relatively few written materials about them. We therefore decided to produce a case study document describing some of the key current activities of such Groups. Two thousand copies were produced and these have been widely distributed and well-received. After foreword and introduction from our President and Chairman respectively, *Moving Beyond Them And Us* included the following headings:

- The work of Patient Participation Groups
- The organisation of Patient Participation Groups

- Patient Participation Groups and the Changing NHS
- Useful Contacts
- A history of the early years of Patient Participation Groups

4. Picker Institute research

In Spring 2006, we became aware that our understanding of the involvement of black and minority ethnic communities was not as rich as we would like. We therefore commissioned the Picker Institute to undertake original research in this area. This had three themes. First, they added to our stock of good practice examples. Second, they disaggregated the national survey of general practice to learn more about the views of specific black and minority ethnic groups. Third, they provided a simple brief describing the particular health needs of different ethnic groups. This has proved a valuable resource and has been widely disseminated by the Picker Institute itself.

5. Minority Matters

Drawing on the Picker Institute research and on our own experience, we captured our learning about the involvement of minority groups in a simple 12-page document that was widely distributed, including to every English PCT and all of our affiliates. It was organised under key themes:

- Meeting a clear need
- Community initiative
- Getting the language right
- Empowering communities
- Training
- No one size fits all

6. Major survey of patient participation in primary care

In 2005, we wrote to 6 practices in each PCT across England including two surveys. One survey was to be completed by practices with a Patient Participation Group, the other was to be completed by practices without a Patient Participation Group. Although the boundaries of the PCTs changed, we then sent the full survey to six different practices in the historical PCTs when we repeated the process in 2007. The response rate was nearly 30% and headline findings are as follows (see Appendices for the full report):

- The percentage of practices who reported having a PPG rose from 27% in 2005 to 37% in 2007
- By 2007, 77% of practices without a PPG had considered establishing one. Their decision not to proceed was most commonly explained by a lack of time. Other reasons included:
 - a feeling that the practice was already close to its patients
 - perceived lack of interest among patients
 - fear that the wrong patients will be interested

- the difficulties of working with a diverse patient population
- a previous failed attempt at establishing a group
- In 2005, 44% of practices with a PPG felt that their Group was quite or very influential in the life of the practice. Only 7% reported that the PPG was not at all influential. These figures were 38% and 8% respectively for the 2007 survey, reflecting the fact that many more groups were newly formed. By contrast, only 13% (10% in 2007) felt that the PPG was quite or very influential in the life of the PCT with 54% (65%) feeling that it was not at all influential at that level.

7. Pilot Scheme with 25 Patient Participation Groups

In Autumn 2006, we launched a pilot scheme to provide more intensive support to 25 of our affiliates. Each of the pilot sites received a lengthy phone call to establish their baseline and nearly all of them received a personal visit from one of four N.A.P.P. coordinators. This allowed learning to be shared across our network and was reinforced by a miniconference held in Eton at the end of June 2007. Fourteen PPGs were represented there and the findings are outlined in the conference report, again provided in the Appendices.

The pilot sites themselves also completed a straightforward evaluation to describe their learning and progress during the scheme. This highlighted the value of networking opportunities and of visits from N.A.P.P. representatives. The pilot process has also confirmed our existing belief that Patient Participation Groups can only be truly effective if the practice as a whole (especially the doctors and practice manager) is supportive of their work.

8. Development of training materials

We are aware that there is an imbalance between the resources available for training members of the public who are involved in statutory activities (notably PPI Forums) and those who engage in non-statutory work. We sought to address that gap by developing training resources, in partnership with Oldham and Preston Primary Care Trusts. The materials are supported by a DVD where patients were asked to describe their experiences of trying to influence the NHS.

The draft training resources have been sent to fifteen Primary Care Trusts for comment and are organised under the following headings:

- Why do Patient and Public Involvement?
- Patient Participation Groups
- Fairness, Equality and Diversity
- Understanding the NHS
- Committees and teams
- Key skills for public involvement work
- Public involvement techniques
- Leadership and facilitation

9. Monthly ebuletin

As part of our dissemination strategy, we have introduced a monthly ebuletin. This is sent to all of our affiliates and to all of our named patient and public involvement contacts in English Primary Care Trusts. It is also shared across the NHS Alliance network. Feedback to date has been positive and we hope to continue this now that the Section 64 funding has ended.

10. Redesign of N.A.P.P. website

The website has been a crucial resource in disseminating the best practice findings. We now receive 400-500 hits per month with a significant increase over the past 12 months. The redesign allowed us to group the learning under a best practice heading. We also started to write ten minute guides to address some of the key policy changes (see, for example, our ten minute guide to Patient Participation Groups in the appendix) but discontinued this when we became aware of the extensive signposting materials developed by the Healthcare Commission.

11. Regional Workshops

Three regional workshops were held in 2006, in Derby, Coventry and Exeter with a combined attendance of seventy. They were co-funded by Connecting for Health who used half the day to discuss issues relating to the electronic health care record. The remaining half day considered challenges and opportunities relating to patient participation in primary care, and were a further opportunity to share the learning to date.

12. Academic research

We have linked closely with Paul Bagley at the University of Birmingham as he undertook a comprehensive literature review relating to Patient Participation Groups in primary care. Our role has been to comment on drafts and to suggest useful sources of information. Paul's work has been incorporated into the research digest that was issued by the NHS Centre for Involvement in Spring 2007. This can be found at:

<http://www.nhscentreforinvolvement.nhs.uk/docs/Evidence%20based%20digest%20-%20issue%201%2C%20March%202007%20final.pdf>

13. Dissemination

In addition to the research and dissemination methods described above, N.A.P.P. has also met with, and presented to, a wide range of groups and individuals. These include (though some have since reconfigured):

- ✓ Appointments Commission
- ✓ Council for Ethnic Minority Voluntary Organisations
- ✓ Developing Patient Partnerships
- ✓ Centre for Ethnic Minority Voluntary Organisations
- ✓ Greater Manchester and Cheshire Cardiac Network

- ✓ Healthcare Commission
- ✓ Institute of Healthcare Managers 2006
- ✓ National SHA PPI leads
- ✓ NHS Alliance
- ✓ NHS Centre for Involvement
- ✓ Picker Institute
- ✓ Princess Royal Trust for Carers
- ✓ RCGP Patient Partnership Group
- ✓ Scottish Practice Managers' Conference 2006
- ✓ Socialist Health Association
- ✓ University of Birmingham
- ✓ Essex SHA PPI Network
- ✓ Leicestershire, Northamptonshire and Rutland SHA
- ✓ Oldham PCT
- ✓ Preston PCT
- ✓ Wycombe PCT
- ✓ Richmond and Twickenham PCT
- ✓ Tendring PCT
- ✓ Southend PCT
- ✓ Basildon PCT
- ✓ Easington PCT
- ✓ Greenwich PCT
- ✓ North East Lincolnshire PCT
- ✓ Southwark PCT
- ✓ Reading PPI Forum
- ✓ Wokingham PPI Forum

14. Conclusions

It would be a mistake to compress the extensive work undertaken to date into a small number of simplistic conclusions. The research has been extremely helpful, however, in identifying future priorities for N.A.P.P. These are:

- ❖ To secure consistent funding streams to enable us to meet the current levels of interest in patient participation within primary care
- ❖ To develop a stronger network of local volunteers
- ❖ To increase our capacity to share information between Patient Participation Groups

We would be pleased to provide any further information or clarification that is required.

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Attachments:

The Picker Institute Report
Moving Beyond Them And Us
Minority Matters
Survey findings
Report on miniconference
Training resource part one
Training resource part two
Summary of CfH workshops

