

Patient and Public Involvement Forums'
Annual Report 2006-007

National Summary



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Foreword

by Sharon Grant, Chair of the Commission on Patient and Public Involvement in Health

As I write this, the Local Government and Public Involvement in Health Bill has just received Royal Assent and the future of Patient and Public Involvement (PPI) in the NHS will now lie with Local Involvement Networks (LINks) as PPI Forums and CPPIH will be abolished on 31 March 2008.



These changes are happening at a time when major reforms are being rolled out throughout the NHS and true engagement with patients and the public is needed more than ever.

However, it is right then that this National Summary celebrates the commitment and hard work of thousands of volunteer PPI Forum members. Their dedication has been all the more remarkable considering the uncertainty Forums have faced over their future. Our current challenge is to ensure that the unique knowledge and experience held by Forums is not lost as a new system is planned, and to ensure that PPI Forum members can find a place within it.

Since December 2003, PPI Forums have been working across England, to bring the views and concerns of patients and communities to the forefront of local NHS decision making and, on occasions, onto the national agenda. With almost 4,500 volunteer members, PPI Forums have worked with their associated Trusts to respond to local opinion and to improve the patient experience. The PPI Forums all produce their own individual annual

reports, which are directly available from the Forums.

It is perhaps surprising that in only their third full year of operation, PPI Forums have matured and developed as well as they have. Most have developed their own local networks, others have worked jointly on common concerns and many have come together nationally on major campaigns. Between 2006-2007, PPI Forums launched three important campaigns. The first, 'Food Watch', looked at patients' experience of hospital food. The results were quite damning in places, with Trusts inconsistent in what they provided to patients, to such an extent that a high proportion of patients told us they had their meals supplemented by food brought in by their family and friends.

The second campaign, 'Care Watch', explored the true nature of dignity and care in today's NHS. While the results showed that most patients were happy and understanding about the care they received; there were still too many instances of patients needing help with eating and access to toilet facilities. The survey also highlighted that the use of mixed-sex wards is

still far too common and highly unpopular. Both campaign reports were sent to the Department of Health and the findings of Care Watch in particular are being used by the Department of Health throughout their Dignity in Care campaign work. The third and final campaign, 'Dentistry Watch', highlighted the extremes patients are faced with in their inability to access an NHS Dentist, with many forced to go private, whilst a small proportion undertook self-medication to the alarm of the national and international media and parliamentarians. The campaign received unprecedented media coverage, but more importantly has led to the instigation of a Health Select Committee Inquiry.

PPI is about people. It is about the thousands of volunteers who since December 2003 have committed their time and energy to make a difference to millions of local people. The fact that we celebrate success and not highlight disenchantment is a testament to Forum members who have continued to fulfil their responsibilities, no matter what was thrown at them, and that includes their proposed abolition announced in 2006.

The challenge for LINKs will be to harness the impressive momentum created by Forums and to ensure that the learning and skills that members both brought to and developed in Forums, is not lost. Not only do Forum members need greater clarity over the role that they can play in a LINK, but also confidence that LINKs will succeed and deliver the wider engagement that is wanted by all involved. Crucial to ensuring that these individual volunteers continue to be involved – both in their current role and as a potential LINK member – is minimising the gap between the end of PPI Forums and the beginning of LINKs.

Worryingly, the Department of Health has moved from a position where there would be no gap, to one where a gap is actively being accepted. Not only will a gap pose issues for public confidence in the NHS at large, but could lose the interest of potential LINK members. Both the Commission and

the PPI Forums will face the approach to 2008 with some degree of apprehension.

However, I am confident that whatever the future brings, PPI Forums have a solid legacy of which they can be rightly proud, made up of real successes both national and locally. The beneficiaries of this have of course been patients themselves and their carers, but also in the longer term the wider public who will in future demand a sense of ownership of their NHS, by being able to shape services and policies in health as never before.



Sharon Grant
CHAIR

Introduction

At the end of March 2007, there were 397 PPI Forums. This was a reduction from 572, through merging Forums, following the Department of Health initiated reconfiguration of Primary Care, Ambulance and Mental Health and Learning Disability Trusts.

This gives each Trust an independent 'critical friend' to work closely with - but a 'critical friend' with a clear responsibility to represent the views of patients and their local communities. Each PPI Forum develops their own work plan by deciding which local health issues and services need investigating and how to give local communities the chance to contribute to shaping health services. Their work includes gathering views about the quality of services, discovering any gaps and providing ideas on improving the experience of people using services. Forums produce individual annual reports for the year, which runs from April to March, which are copied to the NHS Trust concerned.

This annual summary of these individual reports provides a snapshot of the varied work undertaken by PPI Forums from Northumberland to Cornwall, Shropshire to Norfolk.

Work plans are based upon local issues and concerns that have been identified by the Forum. Some may have also have a national impact – such as hospital food and the quality of care in hospital - while others may be unique to the experiences of the community they represent.

Now in their third full year, PPI Forums have become a loud and effective voice for the people and patients they represent. The improvements that they have helped to make, despite continued uncertainty over their future, demonstrate the real progress that is being made by giving patients and local communities not only a voice, but a seat at the table when decisions are being made in health and healthcare services.

The Commission for Patient and Public Involvement in Health provides support for PPI Forums, ensuring that their voice is heard in health matters. Voluntary sector and not-for-profit organisations are contracted by the CPPIH to provide local Forum support (Forum Support Organisations) including administrative duties. The public profile of Forums has been raised through many press and broadcast media opportunities, making stakeholders aware of the benefits they bring to the people they represent.

However, the remit of PPI Forums is wider than monitoring quality and making recommendations about health services. They also look at the health impacts of social care, transport or housing. PPI Forum members have looked at a wide range of issues over the last year, with infection control, health services and facilities, GP services, transport and parking featuring in a majority of PPI Forum work plans throughout the year. Encouraging the NHS to



become a truly patient led service, PPI Forums have:

- ensured issues which really matter to patients and their communities are highlighted and changes made where necessary
- provided not only a local voice for patients and the community but a national one on key health issues
- ensured the involvement of under-represented groups in health decision making
- monitored services and ensured where there are problems these are addressed

Key areas where Forums are making a difference

Patient Forums strive to ensure the NHS continues to deliver and improve, listening to the views of patients and their communities.

With over 300 PPI Forums working in different areas of the country, a vast amount has been achieved. Working locally, Forums are able to pick up on the issues that really matter to communities. They have brought about changes both big and small. The small changes should not be neglected as it is sometimes these, which make the biggest difference locally.

Highlighted in this publication are just snippets of some of the work PPI Forums have been carrying out for the last year on behalf of their communities.

1. Working with their Communities



PPI Forums work to reflect the views and represent all communities living in their local area.

To achieve this, Forums have used a wide variety of methods to meet, understand the needs and collect the views of the different communities living in their area. Over the last year Forums have come up with a number of creative initiatives to engage with their communities, also ensuring that the views of those often under represented groups are listened to and acted upon.

Below is just a small sample of some of the work being done in this area:

An innovative new Health Reference Panel established by the **PPI Forums in Manchester, Salford and Trafford** is now providing a creative, practical way of engaging with people in the local communities who are unable to commit to full-time PPI

Forum membership. The panel consists of individuals, groups and organisations with an interest in health, who are kept informed about the activities of the Forums. In return, they are periodically asked to provide their views and experiences and have input into work and discussions on health and health services.

This is proving to be an excellent way of capturing the views of the broader community. All of the feedback received is passed directly to the Forums and can be included in specific reports, although comments remain anonymous.

South West Kent PCT and Maidstone Weald PCT Forums piloted a suggestion box at the Kent County Show which received 300 responses from attendees about local health services. As a result of the success of the

scheme, suggestion boxes were subsequently installed in 37 surgeries across South West Kent and Maidstone and Weald. Forums have received many comments from patients and ensure that any relevant issues are taken up with the Trust.

Dorset PPI Forum co-ordinated a joint community engagement event with members of **Hampshire PPI Forum**. The Forums wanted to discover whether people who are living close to county borders experience problems accessing health services. It was also an opportunity for local groups and the public to provide ideas and suggestions to improve local health services.

More than 30 people from many different community groups such as Friends of Local Hospitals, Carers' Groups, Parish Councils, voluntary organisations and members of the public attended to express their opinions and feedback from the event was used to inform future Forum work plans.

Working with Younger People

Cornwall Partnership PPI Forum highlighted concerns over services for children and adolescents with mental health problems. The Forum identified several issues including communication breakdown between organisations, access to services and the amount of information



holding a “Come Dancing for Health” event, in conjunction with Manchester PCT and South Manchester Healthy Living Network. It was attended by more than 70 older people also who received blood pressure checks and information on the health benefits of ballroom dancing. The event received media interest and prompted interest in the Forums.

available to young people. The Forum also held a series of workshops where partnership organisations came together. Delegates included the Children and Mental Health Service’s (CAMHS) Commissioning Manager and Cornwall Partnership Trust and Health Promotion, an organisation working solely for young people with mental health problems.

Following these workshops CAMHS submitted a proposal to review services.

The Heart of England Foundation Trust PPI Forum was involved in the creation of a Youth Forum at Heartlands Hospital.

The initiative was very well received and involved a number of groups and organisations including Heartlands Hospital, the Solihull Muslim Community Association and Washwood Heath Youth & Community Network. The Trust welcomed the results and subsequently agreed to take over the running an administration of the Youth Forum.

Working with older people

The Milton Keynes Hospital PPI Forum in partnership with Age Concern undertook a survey of older people to discover their views on hospital treatment and after care in the community. The survey consisted of a questionnaire which was used to target patients following discharge from hospital. Age Concern hosted a lunch and invited recently discharged patients to gather their comments and views on discharge procedures.

The Manchester Health Watchdog PPI Forum started 2007 with a kick by

Working for the Homeless

The PPI Forum for Derbyshire Mental Health Services helped set up a group to represent those involved with homeless people in the public and voluntary sectors. This followed on from the success of a Homelessness and Mental Health Conference that they held in February 2007, The Homelessness and Mental Health Group meets regularly and has developed protocols to ensure better access and service provision.

The Northamptonshire PPI Forum interviewed homeless people at a local





support centre in Northampton. A report was produced and the findings were highlighted in the Forum's commentary for the Healthcare Commission's Annual Health Check. From this initial piece of work, issues have been identified such as problems in accessing services when a person does not have an address, homeless people being discharged from hospital back onto the street and that, while there are individual services for homeless people, there is no overall strategy to ensure that these are 'joined up'. Further meetings have been organised to gather information and plan future work.

Working with people who have different needs

11 Mental Health PPI Forums in London collaborated together to publish a report and best practice guide entitled "Unheard Voices – listening to the views of Asylum Seekers and Refugees". The report was supported by an All Party Parliamentary Group of MPs and

built on research and interviews with asylum seekers and refugees. It made over one hundred recommendations and concluded that poverty, housing and immigration status are the key issues impacting upon the mental health of asylum seekers and refugees.

Neil Gerrard MP, Chair of the All Party Parliamentary Group on Refugees, said:

"I very much welcome this report and its recommendations. If we can put this best practice guide into effect it will have really positive effects."

The PPI Forum for Mental Health in Oxfordshire and Buckinghamshire held four workshops involving people from the black and ethnic minority communities to identify their views and concerns about mental health provision.

The Forum produced a report identifying a number of key issues and forwarded this to the Oxfordshire and Buckinghamshire Mental Health Partnership NHS Trust.

The Trust looked at each of the issues raised which included some counselling services being only available in English, a lack of workers able to identify with other cultures and lack of representation from the Black

and Minority Ethnic (BME) community in the Early Intervention team. The Trust then identified an Action Programme to address those issues which were their responsibility.

The report is a standing item on the regular Forum/Trust meetings which ensures that progress is monitored regularly.

The report has also been forwarded to the Commissioners of Mental Health Services and other providers of Primary Care to enable those organisations to respond to relevant concerns and guide future commissioning decisions.

Following a presentation given by the Refugee Council on the 'First Do No Harm Report' the PPI Forum for Birmingham East & North gathered further information and formally responded to the Joint Commission of Human Rights and Refugee Council on the issues raised by the report.

The Forums highlighted their concerns about the current NHS policy to charge Refugees and Asylum Seekers for healthcare under the NHS; and refusing to treat them unless they have an immediate or life threatening condition in which instance they will be charged after treatment.

2. Monitoring and Reviewing NHS Services



A crucial part of the work of Forums is the ongoing review of NHS services. Forums regularly undertake consultations and survey the public and patients to ensure that services are meeting their needs. Information from this work is used to help Forums decide on areas which require attention and they report any findings or observations back to the Trust. Forums work closely with Trusts to ensure that the voice of the patient is heard and that any reviews or changes to services involve service users early on in the planning stages. Forums also actively monitor NHS service provision looking at a range of areas such as hospital food, GP services, hospital acquired infections and maternity services to name but a few.

The following are some examples of Forums' work in these areas:

Hospital services

NHS Trust Forums work with their local hospital to ensure that they are meeting the needs of patients. Forums will

monitor services and regularly carry out patient surveys around areas such as hospital food and hygiene for example to ensure the service being offered is up to standard.

In response to hospital ward closures and delayed discharge issues, the **Brighton and Hove PPI Forum** conducted a programme of monitoring visits to local intermediate care facilities. A report with recommendations was submitted to South Downs Health NHS Trust and an action plan developed. In particular, the Forum identified that more intermediate care beds are needed urgently and have asked the PCT to provide them.

Many Forums work with their Trust to monitor hygiene and cleanliness in healthcare settings. Hygiene inspections are now a regular activity and Forums will use them to highlight to the Trust areas for improvement.

The **University Hospitals of Leicester PPI Forum** is the lead on the Leicestershire and Rutland Forums Hygiene and Infection Control Committee. It has a well established programme of inspections in the three hospitals and enjoys the understanding and support of the staff and management, which has led to many improvements. Some of these changes have included the introduction of regular changing of shower curtain, replacing shower pull cords, replacing paper notes with wipeable case notes and opening windows which had

been previously nailed down. Follow up inspections are a feature of the work programme and are seen as a stimulus to continuing improvements.

Hospital food has been an area of national concern for Forums this year and Forums conducted a national campaign, entitled 'Food Watch' to find out the views of patients. (You can find more details of this in the Forum campaigns section). Below is an example of where a Forum has taken the Food Watch initiative one step further.

The Norfolk & Norwich University Hospital PPI Forum was made aware of a problem concerning the quality of inpatient catering service and patient satisfaction through participation in the national 'Food Watch' survey which received over 80 respondents. Results of the local Food Watch survey were so at odds with the findings of the Trust's PEAT inspection that it obliged the Trust to set up a committee called 'Food Watch Committee' to review, agree and implement improvements in standards. Forum members were actively engaged in these committee meetings which are now an ongoing process. As a result of the survey there were monthly meetings, the first of which addressed all the issues raised from the recommendations in the Forum's report. e.g. quality of food, temperature, nutrition, lack of menus, communication & information, presentation of food, assistance with feeding etc. and an agreement to run future review surveys.

A public meeting was held and improvements to date include: a staff member promoted to oversee the delivery of food; new procedures and signs have been implemented to give feeding assistance for incapacitated patients; the Restaurant Users Group includes a Forum representative; every member of the catering staff has undergone re-training and there is an improved menu format. The Food Watch Committee became subsumed into a "Nutrition on Wards" Committee which has continued this work and whose brief is to improve hospital nutrition. The Norfolk & Norwich University Hospital is backing the Forum initiative and has been keen to implement improvements.

GP services

PCT PPI Forums also monitor and inspect GP services to ensure they are fit for purpose. Over the last year Forums around the country have carried out surveys around GP access, communication and opening hours amongst other areas.

When patients were left without a GP after their local doctor died suddenly, members of the **South East Essex Forum** facilitated meetings with local residents to find out what services local people wanted from a new GP. One of the main findings was a keenness to retain the current premises for future GP services.

As a result of this work by the Forum, in conjunction with the local community, the PCT agreed to suspend the planned closure of the premises and to thoroughly research the needs of local people in order to devise a solution which would be acceptable to all residents.

Out of Hours

Many Forums have been concerned with the NHS Out Of Hours service this year after receiving many complaints from patients.

The **East of England Ambulance Service PPI Forum** discovered that the North Norfolk, Southern Norfolk, Norwich and Broadland PCTs Out Of Hours (OOH) service provided by district nurses and their drivers was under threat. As a result, the Forum wrote a letter to the local press, made contact with district nurses and their drivers, Norfolk MPs were lobbied and the Forum organised a meeting, which was attended by representatives of the PCTs, local MPs, district nurses, their drivers and a representative from Anglian Medical Care (AMC) part of the Ambulance Service, running the current OOH service in Norfolk and Waveney to discuss the problem.

As a consequence the AMC agreed to employ the district nurses and their drivers to ensure that the quality of service to patients would be maintained which delighted the

Forum particularly as it showed that the AMC recognised the importance of the first class care given to patients by the OOH district nurses.

3. Involvement in Consultations



Additionally, members visited community groups and public events, publicising the consultation and assisted people to fill in the forms and communicate their views. The findings were fed back to the 'Making it Better' Consultation team.

The Forums received 200 completed forms and found that many of the people they spoke to were unaware of the consultation, but said that the Forum's summary documents were very useful.

Section 11 of the Health and Social Care Act places a legal duty on NHS Trusts, Primary Care Trusts and Strategic Health Authorities to involve and consult patients and the public on substantial changes to services.

This includes:

- the ongoing planning of services
- considering and developing proposals for change
- decisions that may affect the operation of services.

Many NHS Trusts ensure they consult and involve their local PPI Forum, when planning any major changes to service. In addition Forums will often seek the views of patients and the public on consultations through public meetings, media campaigns and surveys to ensure the voice of patients and the public is fed back

into the decision making process. Forums have used their links with the community to reflect people's views and make a real difference to consultations, ensuring that any changes to service reflect what local people want and need. For example:

Salford PPI Forum helped play a major role in encouraging responses to a major NHS consultation 'Making it Better' in North West England. The consultation was looking at changes to healthcare services for young people, parents and babies which would affect 3.1 million people across the area. A possible outcome for Salford was the withdrawal of children's, neonatal and maternity services from the local Hope Hospital.

Keen to ensure residents had their say on the consultation, the Forums developed a series of summary documents, and a questionnaire simplifying the original consultation papers.

Due to the large numbers to be affected, on March 6 it was announced that the Secretary of State for Health had asked an Independent Reconfiguration Panel (IRP) to conduct an independent review of the 'Making it Better' proposals. The reports from the IRP are expected soon.

Milton Keynes PCT PPI Forum helped to halt the closure of a podiatry service in Milton Keynes, after responding to the consultation initiated by the Milton Keynes Primary Care Trust. The Forum put forward the community's views and asked the Trust to look at all the financial implications of the proposed changes. As a result the PCT decided to withdraw their plans.

After the Forum received notification from the Trust that they were looking at decommissioning the local podiatry service, they set about finding out what impact this would have on patients. The Forum discussed the

issue with various local voluntary and statutory organisations and found that many felt that the Podiatry services were needed.

The Forum called in Age Concern, which offers advice on podiatry programmes around the country, to ask their opinion on how the closure of the service would affect patients. Together they met with the PCT to ask them to reconsider the steps they were taking.

The Forum made the case that the costs saved from withdrawing podiatry services were negligible but the effect on the public was huge. As a result, Milton Keynes PCT agreed to withdraw their proposals and to fill some of the existing podiatry vacancies in order to create a proper and efficiently run service.

Over 100 West London residents attended a major event at Hounslow Civic Centre to discuss the health implications of the planned Heathrow airport expansion. The meeting, organised by **Hounslow PCT PPI Forum**, gave the community an opportunity to voice their opinion on the planned expansion of Heathrow airport and how it could impact upon their health.

The Hounslow PCT PPI Forum also invited a range of speakers to attend the event, including specialists on the effects of air pollution on respiratory problems, transport campaigners, local councillor and Lord Soley of Hammersmith.

The event hosted a lively debate on the planned expansion. Following the event, the PPI Forum wrote to Secretary of State for Health, Alan Johnson to demand a review of the Heathrow situation.

Working closely with the County Overview and Scrutiny Committee, **West Wiltshire PCT PPI Forum** became heavily involved in the 'Pathways for Change' process. This was a major consultation run by the local NHS, which looked at the future of healthcare in the area. The Forum has invited by the Trust to attend meetings and promoted the consultation with the public. After listening to the views of the community, the Forum was asked to comment on the project's consultation document and made a number of changes to reflect the needs of the community.

PPI Forums for Bournemouth & Poole PCT, Royal Bournemouth & Christchurch Hospitals, Poole Hospital, Dorset PCT and Dorset Healthcare along with other stakeholders were asked to contribute to the development of a protocol for joint scrutiny around the local area.

The purpose of the protocol was to set out the principles, commitments and responsibilities of Bournemouth, Poole and Dorset Councils, local NHS bodies and PPI Forums for the conduct of effective health scrutiny. Following consultation, the draft protocol was re-written to include all

of the suggestions put forward by the PPI Forums and distributed in March 2007. The protocol is now up and running and was used in April 2007 by Dorset Healthcare NHS Foundation Trust to evaluate their Clinical Services Review. A Forum member took part in the impact assessment of the Review.

East Riding PPI Forum worked with the **PPI Forum for Scarborough & North East Yorkshire Healthcare** to organise a meeting in public to discuss the Acute Trust's consultation on the future role of Bridlington Hospital. After listening to concerns from the community, the Forum decided to support the 'no change' option, but with variations around community health service provision and improved Trust management. They also requested that the issue of consultant cover at the Hospital be addressed.

4. Working in partnership

Since 2003 PPI Forums have been working alongside their local NHS trusts and their relationships have been ever developing and strengthening. This ensures that PPI Forums are widely recognised as an important stakeholder with their input welcomed and valued.

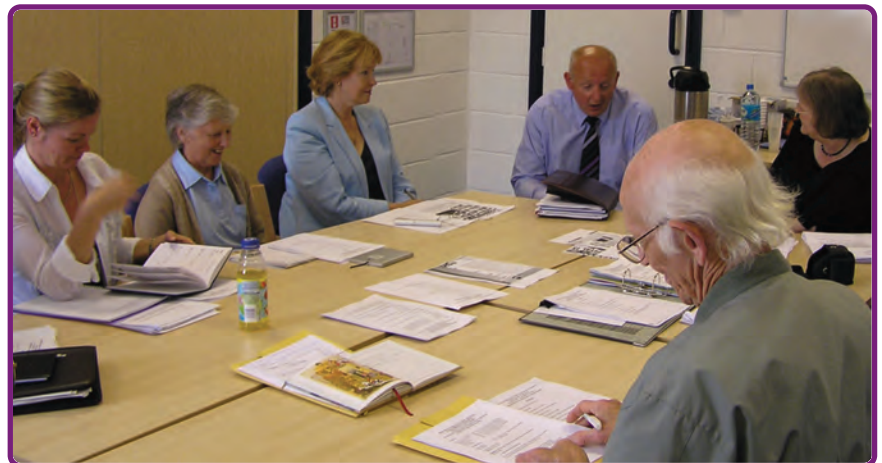
The PPI Forums also have a strong relationship with the Healthcare Commission and play a crucial role in the Healthcare Commission's Annual Health Check. Last year 485 PPI Forums took part in the Health Check, providing a declaration on how they consider their local NHS Trust is meeting core standards.

Forums also continued to develop relationships with stakeholders such as National Institute for Clinical Excellence (NICE), Overview and Scrutiny Committees (OSC), MPs, local health groups, schools and universities.

Some examples of how Forums work in partnership are:

The **PPI Forum for University Hospitals, Leicester** worked with their local NHS Trust to ensure that budget reductions imposed on the Trust had a minimal impact on patient services.

Despite previous budget reductions, there was further pressure this year on the Trust to save money and the PPI Forum felt this was threatening patient care.



Following suggestions from the PPI Forum the Trust agreed that meetings about these reductions should take place in public and involve the Forum. Through this the Forum were able to ensure that patient interests remained at the heart of the decision making process.

Nottingham City PPI Forum worked with Nottingham City's OSC to review the quality of service provided by the City's new NHS Walk-in Centre.

The Forum carried out a large number of patient interviews to gain an understanding of the quality of service provided by the Centre. In addition, Forum members undertook a number of visits to the site to observe the standard of the building and the facilities provided. This led to the Forum making seven recommendations to the PCT about how they might improve their services.

The work of the Forum was commended by Nancy Watson, Nottingham City Scrutiny Officer who said:

"The PPI Forum provided invaluable support to the Health Scrutiny Panel's review of the Walk-in Centre. Their patient interviews and feedback from site visits gave the panel an insight into services from the patients' perspective."

PPI Forums in Staffordshire worked with their local council to establish improved bus services between two major hospitals.

After receiving feedback from patients struggling to attend appointments due to a lack of adequate public transport, the **PPI Forums for Mid-Staffordshire General Hospitals and for Cannock Chase** came together to source a solution.

The Forums joined further partnerships with the local council's transport department, the Hospital Trust and the Cannock Chase Primary Care Trust.

The partnership proved highly successful. The Council agreed to invest £166,000 so as to introduce a new bus service providing regular transport between Staffordshire General and Cannock Chase Hospitals.

Staffordshire County Council also agreed to allocate £600,000 to provide five drop floor entranced buses for the route, to ensure that the bus service is easily accessible to wheelchair users or anyone with mobility problems.

The success of this service has also helped to alleviate car parking problems at the hospital and reduce car usage.

As part of the ongoing campaign to reduce the risk of transmitting infections the PPI Forum members joined forces with the **George Eliot Hospital's** Infection Control Team and ran a 'hand hygiene' awareness event.

Visitors and patients at the George Eliot Hospital are being urged to play their part in the fight against infection by following simple but effective measures such as thoroughly washing their hands as they enter ward environments.

As part of this campaign the PPI Forum promoted the importance of good hand

hygiene and visitors were given the opportunity to check how clean their hands were with a 'glow box'.

The PPI Forum South Tyneside is just one PPI Forum that has established monthly meetings with its Trust's patient involvement officers.

These offer an opportunity to pre-empt or quickly resolve issues. For example; there had been ongoing problems with the South Tyne PALS service regarding staffing within the service. These issues were raised with the Trust which worked with the Forum to look at ways to resolve the concerns.

Milton Keynes Hospital PPI Forum carried out an evaluation of the Imaging Department, in partnership with Milton Keynes General Hospital.

The aim was to obtain patients' views on the imaging service in Milton Keynes Hospital and communicate these to health professionals and services users to assist in developing the service. In total there were 1,230 surveys issued over the two weeks. The resulting recommendations were forwarded to the Hospital and action plans were then put together to implement them.

Communication

Many NHS Trusts seek the advice of PPI Forums on the design of information materials aimed at the

public. Forums help to make sure that trusts communicate to service users in a way which will be understood by service users.

A **Kettering General Hospital Forum** member sat on the Patient Information Committee for the new Treatment Centre and contributed to the information leaflets provided for the Centre, making sure the information could be understood and was relevant to all patients and members of the public.

The East of England Ambulance Service Forum worked with the Trust to design and implement a number of patient information and aftercare leaflets to be carried on ambulances in Essex. One leaflet focussed on unexpected deaths, as a result of a suggestion from the Forum which had received information highlighting misunderstanding around the process that needs to be followed after an unexpected death.

Following lengthy negotiations between the Trust and the Forum, the Trust agreed that all patient aftercare and information leaflets will be carried on ambulance vehicles. The system was instigated in liaison with the **Essex PPI Forum** and has now been adopted throughout the rest of the eastern region. This includes a diabetes aftercare leaflet produced by Forum members in East Anglia.

5. Forum Campaigns



In the past year, PPI Forums across England have joined forces to deliver a number of health campaigns around areas of national concern. Forum members throughout England have identified key issues which would benefit from their national scrutiny and following up on complaints from patients and the public, Forums set about asking users of the NHS for their opinion on a number of services. Issues they have looked at this year include Hospital Food and Dignity and Care within the NHS.

These campaigns have succeeded in bringing the opinions of patients and the public to the forefront of health decision-making as well as stimulating national debate around areas that matter to NHS users.

In addition to the CPPIH led national campaigns, for the past two years

Forums have also been invited to submit an independent commentary on their trust's performance as part of the Healthcare Commission's Annual Health Check process. The Healthcare Commission use the annual health check to measure how well NHS trusts are performing against the Government's Standards for Better Health.

As part of the Annual Health Check, every NHS trust publishes a self-declaration, signed-off by the trust's board, on the extent to which they are meeting the standards. The Healthcare Commission then uses a range of publicly available information, and feedback from patients and the public, to cross-check the trusts' declarations. The commentary provided by Forums is part of the feedback from patients and the public that helps the Healthcare Commission satisfy itself

about trusts' performance throughout the year. In the 2006/2007, all 394 Forums submitted a commentary, or informed their trust why they couldn't.

PPI Forums will once again be submitting commentaries as part of the annual health check in 2007/2008.

Food Watch

In Autumn 2006, PPI Forums asked patients and their visitors for their opinions on the cost, quality and availability of hospital food. More than 2,240 people were surveyed at 97 hospitals across England.

The survey found that a number of hospitals were providing patients with what they wanted and needed, but in many hospitals patients were still being provided with food that was not what they wanted and served at the wrong temperature. Patients left it because it was unappetising and the hospital food was being supplemented by food brought in by family and friends.

40 MPs put forward an Early Day Motion requesting Government action to improve the quality of hospital food and the campaign prompted widespread national debate on hospital food.



Sharon Grant, Chair of the Commission for Patient and Public Involvement in Health (CPPIH) commented:

"These findings are disappointing. Patients have every right to expect food that is nutritious, served at the appropriate temperature, meets their dietary needs and help to eat if they need it. Proper nutrition is essential to recovery both physically and psychologically. An additional concern is the strain and cost for relatives who feel obliged to bring in substitute meals".

Alison McCree, Chairman of the Hospital Caterers Association (HCA) commented:

"Despite the negative findings, the HCA applauds the PPI Forums for conducting the survey. By ensuring that hospital food and catering services stay in the public and media spotlight, then there is even greater pressure for them to be treated as priority issues by NHS trust boards".

Forums were surprised by the response from the Department of Health which reported that they thought hospital food was much better than it used to be. Andy Burnham, Health minister, said

"Last year, the independent Patient Environment Action Teams found that 90% of hospitals were rated 'good' or 'excellent' for food standards, compared with 17% in 2002. But we recognise that more needs to be done."

Care Watch

Throughout February and early March 2007, members of PPI Forums asked 2,462 patients across the country for their views on crucial issues which could affect a patient's dignity, such as privacy, communication and assistance with eating.

Results of the survey found that contrary to popular belief, patients believe that the NHS is generally getting patient dignity right. However, the results also showed that as the NHS changes then so do patients' expectations, with many anticipating less personal care than they have had in the past

Following the Care Watch survey, a number of NHS Trusts have taken steps to address the issue of dignity in care and mixed sex wards with the support of their local PPI Forum. Findings were shared with decision-makers at the Department of Health (DH) and Forums were congratulated for their work on the survey.

The DH reiterated the importance of patient surveys and announced that the Forums' findings would form part of the Government's 'Dignity in Care' Campaign.

6. Forum Recruitment and Promotion

The impact of Forums' work on healthcare provision is regularly publicised in the local and national media and to stakeholders. Forums work locally and collaborate on a national level across the country to bring health issues of national public concern to the fore. The publication of such success stories has helped build the reputation of PPI Forums as a force to convey the voice of the public in healthcare decision-making.

Forums have continued to undertake activity as indicated in their workplans, even under the shadow of threat of abolition shortly after Forums began and the proposed abolition which was announced in July 2006. They have actively engaged in their own recruitment and staged community events to raise awareness of their work and to recruit new members from a variety of backgrounds to existing Forums. Some of the activity that they have undertaken to promote their work is summarised below:

Members of Derbyshire Mental Health Services Forum and the Forum Support Organisation attended the Derbyshire Mental Health Awareness Day in October which provided a good opportunity to meet members of the public and raise awareness of the PPI Forum. Information packs and leaflets were given out and many local mental health and statutory organisations attended with information displays.

The Bristol Patients' Forum found it difficult to attract members of the public and local organisations to their meetings. To address this, a launch event (Open Meeting) was organised following the merger of the Bristol PCTs. This one-off event in November was funded by the CPPIH and was publicised through e-mail, posters and local group newsletters. The Locum Director of Public Health for Bristol PCT and Bristol City Council gave a presentation on the department's work across the city which was followed by a question and answer session and a chance to 'network' over lunch. The event was well attended by representatives from local community groups including Avon Somerset and Wiltshire Cancer Services, Princess Royal Trust for Carers and Hartcliffe and Withywood Partnership.

The **Devon Partnership NHS Trust (DPT) PPI Forum** successfully raised its profile during the last year through its work within local communities. The Forum has undertaken a great deal of high profile work which has included projects on South Devon mental health rehabilitation and recovery services, a potential ward closure in Mid-Devon and the provision of care and support for people with learning disabilities and their carers.

Well attended public meetings were held which attracted press, radio and TV coverage. The Forum has varied



the locations of their meetings around the county to give communities in different areas the opportunity to attend. It also distributed a second wave of pre-paid feedback postcards, along with information posters and leaflets clarifying the Forum's aims. The Forum worked closely with the Forum link person at the Trust to publicise the distribution of the cards via the Trust's internal online news bulletin.

The Forum is using the views and feedback gained to further inform their workplan and to ensure that they are addressing the issues that are most important to the local communities. The **Joint Milton Keynes Primary Care**

and Milton Keynes General Hospital PPI Forums organised a Shaping Local Health Event which brought together over 65 organisations and groups.

The event, the largest of its kind held in Milton Keynes, was hailed a success and

- raised awareness of the existence and the role of the PPI Forums
- raised awareness of the wide range of support available to the public and patients through voluntary groups
- made the voluntary groups aware of the range and diversity of the voluntary sector in Milton Keynes and
- raised awareness of the role of the Milton Keynes Acute and Primary Care Trust in delivering services in the community.

At the beginning of the year the **Ealing Hospital PPI Forum** had very low membership, so they decided to raise awareness of the Forum in the local area via the local media, seminars, awareness events and word of mouth. The Forum now has 14 members and has become more involved in a wider range of key health activities.

The Hereford Hospitals PPI Forum used

the Hereford Times to ask members of the public to contact the Forum if they had experiences of MRSA, C. Difficile or other Hospital Acquired Infections contracted by themselves, relatives or friends, whilst an in-patient at Hereford Hospital Trust. Over 30 letters, emails and telephone calls from members of the public were received and those who responded were invited to a public meeting to share their experiences. Twenty seven members of the public attended the meeting and shared their stories with the Forum. Six of these attended the next Forum meeting and raised issues which arose from their experiences at Hereford Hospital. The Forum wrote to the Trust to highlight these concerns and the Trust responded addressing all the issues raised.

The Medway Community Health (MCH) PPI Forum Chair speaks to a local press contact following every Forum meeting to highlight any issues that the Forum is working on. As a result, regular articles appear in the press promoting the PPI Forum and its work. In addition, the local Forums have their own leaflet, and bookmarks which have been distributed to GP surgeries, libraries, council offices, pharmacies and other appropriate venues. During January and February 2007 Forum members made formal visits to two new PCT Local Improvement Finance Trust (LIFT) projects, Lordswood and Rochester Health Living Centres, taking the

opportunity to promote PPI when talking to patients, public and staff.

West Kent PPI Forum provided suggestion boxes to gather information from patients and the public via post-card type cards that are posted back into the box and collected by members. Emerging trends are analysed and concerns are passed onto the PCT PALS or to GP surgeries to resolve or answer. PPI promotional material is always left with the boxes which are located in most GP surgery waiting rooms in the area and have also been placed in local shopping malls

West Kent members promote the work of the Forum by speaking at local Focus and Community Groups taking a suggestion box with them to promote the scheme and often returning with an issue that needs to be taken to the PCT. Members of the Forum were also asked to look at GP patients' surveys under the Quality Outcome Framework, (QOF) which is a national audit of GP Practices. GPs are required to have a lay person look at the results with them to identify improvements and the Forum completed this work by speaking with many GP practices during February and March 2007.

7. Other areas of Forum work

Forums work on a wide range of areas, many of which are specific and important to the communities they serve. Two examples of this type of work are:

Stroke Services

Stroke services is an area in which many Forums have been concerned. The example below shows how one Forum manages to help improve stroke services in their area.

The Heatherwood and Wrexham PPI Forum planned a series of projects to both improve the standard of stroke services and raise the profile of the importance of a comprehensive stroke service within the Trust. The Forum developed an ongoing dialogue with the Trust which contributed to improvements in the Stroke Unit and diagnostic service and kept this service high on the agenda of the Trust. As a result of this work

- Brain scans are at 73% compliance compared to 43% two years ago
- A Care Pathway has been implemented
- Documentation on stroke patients has improved considerably & multi-professional documentation for stroke patients has been developed

- Specialist equipment has been purchased including specialist scales which are very important to a stroke unit
- Rehabilitation goals have significantly improved from 37% two years ago
- They now admit patients directly from A&E
- Speech therapy and physiotherapy has improved.

Mental Health

Mental health has always been an area of high interest to Forums. Forums have worked with a number of different mental health associated groups and a national event for mental health PPI Forums was led by the CPPIH this year. The example below shows how meetings with the Trust have helped one Forum to influence the planning and improvement of services.

Since the appointment in October 2005 of the Director of Families and Children's Services, the Lincolnshire Partnership Forum has met with the Director nine times. These bi-monthly meetings, which have been attended by one of the Forum's sub-groups, have allowed the Forum to become involved in proposed improvements to the Child and Adolescent Mental Health Services

(CAMHS) service. The Director of Families and Children's Services continues to seek the opinions of the Forum, which has been able to influence the planning and improvement of services, particularly in regard to access and treatment.

8. Skills & Support for Forums

The CPPIH undertakes the following activity to support Forums

- Sets up, funds, staffs and performance manages all PPI Forums
- Sets quality standards for, and issues guidance to PPI Forums
- Appoints all members to PPI Forums
- Submits reports to the Secretary of State for Health on how the whole system of PPI is working and advises them about it
- Supports Forums in carrying out national reviews of services from the patient's perspective – collating data from PPI Forums and making recommendations to the Secretary of State and to other bodies and persons it considers appropriate

Forum Support Organisations

Forum Support Organisations (FSOs) are not-for-profit organisations that have been contracted by the CPPIH through a competitive tendering process to provide staff support to PPI Forums. These organisations, independent of the NHS, use their knowledge, experience and existing contacts within local communities to support PPI Forums.

They are single organisations or consortia that play a vital role in helping to shape the future of health provision throughout England.

They are managed on a geographical basis by nine regional centres.

Specifically FSOs support two or more PPI Forums and:

- Help the CPPIH by supporting the recruitment and training of PPI Forums
- Help PPI Forums communicate with each other, the CPPIH and other external networks and organisations
- Arrange for information and guidance provided by the CPPIH to be available to the PPI Forums
- Help PPI Forums to monitor NHS services
- Help PPI Forums play an active role in health-related decision making
- Provide administrative support to PPI Forums

Where the CPPIH is not able to contract with an FSO, an In-House support system for PPI Forums has been developed and implemented.

Additional support is provided to PPI Forums through the CPPIH's offices and staff including communications, training, PPI governance, networking events, and the award winning Knowledge Management System (KMS). The KMS enables Forums, FSOs, the CPPIH, members of the

public and other stakeholders to report on their activities, share information and develop knowledge and best practice.

Training

The CPPIH also runs a comprehensive range of training courses to enable the volunteers who make up the PPI Forums to carry out their roles effectively.

In 2006/07 1760 Forum members attended 220 courses run by the CPPIH.

These training courses cover such topics as monitoring and visits, media awareness, meeting and chairing skills, Practice Based Commissioning and equality and diversity.

Full induction training is also provided for new volunteers, so that anyone from any background or walk of life has the opportunity to play a full role with their local PPI Forum.

9. PPI Forums - facts and figures

When PPI Forums launched in December 2003, there were 4,000 volunteer members.

- Currently we have over 4,250 Forum members
- More than 2,500 of our volunteers have been Forum members for two years or more
- We have enabled an additional 5,000 people to contribute to PPI through Forums
- 52% of PPI Forum members are female, and 48% male
- 84% of Forum members class themselves as white, 6% class themselves as Asian, 4% class themselves as black/or African, 3% other white,
- Initially some members left because was a new system and people didn't know quite what to expect
- Others joined to address a specific concern for a period of time,
- Currently the most common reason for resignation is a change in personal circumstances – usually changes in family, employment or personal health.

10. Future plans 2007/2008

The CPPIH and PPI Forums are working towards abolition at the end of March 2008 following Royal Assent of the Local Government and Public Involvement in Health Bill, the legislation which confirms the abolition, and creation of Local Involvement Networks (LINks) in the place of PPI Forums.

In the meantime, Forums are still actively working according to their

agreed workplans to ensure patients and the public have their say in healthcare decision-making.

Some Forum members have contributed to the transition process by supporting the seven Early Adopter Projects that the CPPIH has been managing on behalf of the Department of Health and attending 'Getting ready for LINks' workshops. They have shared their expertise and given valuable insight

into the current workings of PPI. Additionally some Forum members also contributed to the Health Select Committee's Enquiry into Patient and Public Involvement in the NHS.

Despite the planned abolition, Forum members are still a force to be reckoned with, bringing health decision makers to account to ensure health services are fit for the public and patients.



Shaping Health

Better decisions
Better health

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