

# RESPONSE TO THE HEALTH SELECT COMMITTEE INQUIRY INTO THE FUTURE OF PATIENT AND PUBLIC INVOLVEMENT

## INTRODUCTION

1. This response to the Health Select Committee Inquiry into future patient and public involvement arrangements is submitted on behalf of around seventy members drawn from PPI Forums operating in Bath and North East Somerset, Bristol, Gloucestershire, North Somerset, South Gloucestershire, Swindon and Wiltshire.
2. This report is the feedback of discussion groups considering future public involvement issues that took place at a Members Conference in Warminster, Wiltshire on 1<sup>st</sup> December 2006. Details of the inquiry terms of reference were not known at the time that the Conference agenda was planned – so the feedback is either directly attributed to relevant questions posed by the Committee or included as additional comments.
3. The report has been compiled by staff of the Health Advocacy Partnership, a not-for-profit Forum Support Organisation operating in Avon, Gloucestershire, Somerset and Wiltshire.
4. The views reported as bullet points to each question are as agreed by the members participating in the Conference and are submitted without amplification.

## QUESTIONS POSED BY THE SELECT COMMITTEE

5. **WHAT IS THE PURPOSE OF PUBLIC AND PATIENT INVOLVEMENT?**
  - to become a national / local body and voice of the public;
  - to be the eyes and ears of the public (not the NHS)
6. **WHAT FORM OF PUBLIC AND PATIENT INVOLVEMENT IS DESIRABLE, PRACTICAL AND OFFERS GOOD VALUE FOR MONEY?**
  - to contribute a public perspective to the Healthcare Commission's Annual Health Checks;
  - to carry out and report on health related activities, visits, and surveys;
  - to respond with a public view to crisis's as they arise;
7. **WHY ARE EXISTING SYSTEMS FOR PATIENT AND PUBLIC INVOLVEMENT BEING REFORMED AFTER ONLY 3 YEARS?**

No specific view expressed – apart from the general conclusion that there is a risk of losing experience and expertise – and it seemed to be a bit of a waste of money
8. **HOW SHOULD LINKS BE DESIGNED, INCLUDING:**
  - 8.1 **Remit and level of independence**
    - make patient's voice heard; be the eyes and ears of the public – not the NHS
    - there is a need to retain independence from PCT and other provider organisations;
    - contribute to Healthcare Commission's annual Health check
    - produce Forum Annual Report
    - work with local OSCs and regulatory bodies
    - clear definition of role and responsibilities
    - respond to crisis's as they arise
    - listen and monitor your Trust / patient outcomes
    - have more statutory powers

## 8.2 Membership and appointments

Important to:

- maintain adequate numbers of members to achieve work plan priorities
- determine whether existing Forum members are willing to continue
- keep members motivated and involved
- actively recruit for communities, groups and local people
- achieve continuity and clear communication
- have clearer definition of members' role
- devote time and resources to team building
- set achievable targets in LINK work-plans, and regularly review
- prioritise 'what' members do
- participation should be recognised as a public duty – just like jury service

## 8.3 Funding and support

Important to:

- provide adequate funding to support and complete projects
- avoid time wasting activities
- reduce number of meetings
- enable members to allocate resources
- continual support to complete projects – this has resource implications
- maintain support for hospital visits – and to other facilities

Members discussed question: WHAT TRAINING SHOULD BE PROVIDED TO HELP PARTICIPANTS PARTICIPATE EFFECTIVELY?

- What will LINKs consist of: structure; support organisation; working arrangements; need to know what LINKs do to define training
- Training on "what is a LINK"
- Statutory duties and rights
- Provide information not just training
- Specific training on the issue in hand; ask the right questions
- Relevant communication
- How to conduct and behave in a meeting objectively
- How to communicate with the public
- Calling on experts
- Health and social care education
- Time management
- To know who runs LINKs
- Leader of each network with a clear vision and mission
- Leadership training
- Job description for volunteers and training on this
- Initial – understanding NHS structure
- Explaining how LINKs will work
- Clarity on statutory powers
- Ensuring commitment from a 'sense of belonging'
- Training for specialised areas e.g. visiting; PR; checking Trust Literature etc; Public meetings e.g. use of microphones
- Who will decide? Who is trained at what in which way? government; members of LINKs; support organisation

#### **8.4 Areas of focus**

- Set achievable targets
- Current PPIF activities that should carry forward to focusing LINK activities include:
  - Treatment for long term conditions
  - Staffing levels
  - Infection control
  - Social Care
  - Maternity Services
  - Dentistry
  - Access and Transport Project
  - Carer's Project
  - Patient Choice
  - Mental Health issues
  - Acute – ongoing project work (e.g. delayed discharge; 'essence of care')
- Visits – with a purpose and value

#### **8.5 Statutory powers**

Members discussed question: WHAT POWERS DO YOU THINK LINKS SHOULD HAVE?

- Impossible to say until the actual structure and membership is made clear, but LINKs need to be represented on relevant bodies e.g. NHS Trust Boards, Social Services Committees, O.S.C
- All existing Forum powers should be retained
- To have staffed office in each O.S.C. area
- Right to access – short notice, 1 hour; right to require information
- Find out about complete package of care and monitor
- Right to verify independently what is going on.
- Cover social care and health
- Sit on boards – PCT; hospitals; social services
- Right to know how response to complaints have been carried out
- Check if individuals (with patient's consent) care package has been implemented
- Right to challenge government
- To require PCTs/Trusts to work with LINKs
- Right to monitor and report with recommendations
- Make visits to NHS and social care facilities, including:
  - including short notice visits
  - community hospital / centres

#### **8.6 Relations with local Health Trusts**

- Contribute to annual Health Check
- Right to report on Trust activities and receive a response
- forge independence from PCT and other provider organisations

#### **8.7 National coordination**

- Encourage some projects to be done nationally
- Gather information 'statistically' on one subject – at national level with regional breakdowns

## **9. HOW SHOULD LINKS RELATE TO AND AVOID OVERLAP WITH:**

### **9.1 Local Authority structures including Overview and Scrutiny Committees**

- Contribute to OSC reviews
- LINKs be represented on OSCs

### **9.2 Foundation Trust boards and Member Councils**

- Share membership – foundation members can also be members of local LINKs

### **9.3 Inspectorates including the Healthcare Commission**

- Contribute to reviews and reports
- Suitably trained members to be part of inspection teams.

### **9.4 Formal and informal complaints procedures**

- Receive regular reports on local trends
- Use complaint trend reports as evidence to support work-plan priorities

## **10. IN WHAT CIRCUMSTANCES SHOULD WIDER PUBLIC CONSULTATION (INCLUDING UNDER SECTION 11 OF THE HEALTH AND SOCIAL CARE ACT 2001) BE CARRIED OUT AND WHAT FORM SHOULD THIS TAKE?**

**10.1** Not discussed

## **11. OTHER ISSUES**

The Conference considered a number of other issues – not directly related to questions posed by the Health Select Committee. However, members asked that their views be shared with the Committee as they believe that some of the issues remain relevant. These are:

### **11.1 How can individuals participate effectively in LINKs?**

- Facilitate communication between the public and LINKs e.g. walk in centers; letter; third parties
- Need more information and case studies before people can work effectively
- Who will provide the link between HAP/? and vested interest groups to provide fairness and balance to ensure generic issues are covered e.g. hospital cleanliness
- Existing Forum members could be in a 'pool' to conduct visits etc to hospitals/surgery's etc – members already have CAB checks and training
- Join LINKs
- Join other organisations in strategic partnership; community's
- Encourage people to comment and feed in at 'source' of treatment which is then taken forward to LINKs
- Encourage increased membership to other organisations and LINKs
- Lay inspectors (volunteers)
- Activate communication to general public about LINKs – and to other organisations e.g. W.I.'s; Rotary; Lions
- Focus groups and public meetings
- Start working with young people through citizenship/personal and social education so they become active citizens for life
- Provide a real effective host organisation with contractual remit to involve widest section of community possible

## 11.2 How would you like to see links operate?

- Panel selection – independence; open application; non-political
- Core Group – engender continuity, ideas and sense of membership
- Will need training
- Change the name to distinguish from other 'LINKs'
- Simple access to IT for users and alternative access link - need IT
- people in place for people to 'use' to obtain info
- Good media contacts
- Need a national/body voice – well defined structure
- 'Core Group' needs chair/named contact – defined role of chair/facilitator
- Involvement – sub groups attracting interested people
- Publicity to attract people
- Link with health/social services; care groups – many already contacted, need to build on this
- PPIF Members to be invited to be 'members' of LINKs chance to make use of past experience – committed, continuous membership
- National and local support organisation
- More support than now
- Reasonable expenses
- 'Chief Executive' and admin support
- Vetting of voluntary sector organizations
- Transparent and objective selection of groups and individuals
- Inclusion of non-computer experts
- Support for 'Right of Access'
- Leave of absence for employed members to attend meetings/activities. General consensus to encourage younger members to join, invariably this can only happen if legislation allows individuals to take paid leave from their place of employment. Full support of employers will be needed to make this happen
- Public need to know that LINKs will be permanent not transient
- Remember that PPI/LINKs are voluntary and independent

## 11.3 What can LINKs do to engage the public effectively?

- More planning: learn from mistakes made when setting up Forums; clear focus and expert delivery; clear points of contact
- Promotion exercise: effective marketing; robust properly funded publicity; resources – major! to ring fence – no shoe strings allowed; show that LINKs has power; lack of resources will indicate that government are cheapskates
- Government need to heed feedback from Patient Forums and not repeat the same process with LINKs that they did with PPI
- Inform public and convince them to become involved
- PCTs to be paid on results
- Build profile to dissolve apathy
- To be seen to support the public in their concerns
- Named permanent contact point
- Encourage young people and ethnic minorities to apply

**11.4 What can realistically be achieved for LINK work plans?**

- Depends how hard you work with membership
- Avoid time wasting activities
- Do the best we can with resources we have got
- Use smaller working groups
- Produce Annual Report and contribute to annual Health Check
- Carry out monitoring visits
- More work less meetings
- Guidelines on how to conduct meetings
- Complete 'Must do' items
- Less than you think
- Depends on who is listening to us
- Forward planning with short term activities that are achievable
- Commissioning from PCT's and GP's
- Treatment for long term conditions
- Include social care
- Fully understand NHS and PCT provider issues
- Access issues - transport and parking
- Swiftly identify priorities then swiftly identify project
- Patient choice (Swindon and Great Western Hospital)

- 12.** Conference agreed that these general points do not preclude other comments being submitted by individual Forums or members - recognising that the views expressed reflect the experience of members, which may be different from other areas.