

Memorandum
for
House of Commons Health Committee

2007 Inquiry into Public & Patient Involvement in the NHS

Introduction:

I am a National Health Service user with a long standing (30 years) involvement in service user and carer involvement. Since 1999 that has taken an increased focus on the development patient and public involvement in health and since Dec 2003, specifically on Patient and Public Involvement Forums, the statutory replacement for Community Health Councils.

Since resigning my PPI forum membership in February 2004, disability discrimination being the last CPPIH straw for me, I have done my best to function as an independent watchdog for the constructive development of PPI. In 2005, I set up my own website to further this function (PPEyes) but this was closed down in the Autumn of 2005 by the intervention of CPPIH appointed lawyers who alleged defamation (there is legal precedent that a public body cannot do this). The details of this and the evidence of CPPIH incompetence and equivocality is in the accompanying html dossier.

I have in the past, also, via my constituency MP, Richard Bacon, and direct reference, been in touch with the Health Committee about these issues and I did submit a paper Recommendations on PPI reorganisation to Meredith Vivian in August 2004, some of which remains relevant to you and which I have also included.

There seems to have been a surprising absence of organised service user led research in this sphere, particularly since service users and carers "have battled to get their voices heard as credible, legitimate and truly independent - free from attempts at interference and influence by professionals and free from attempts to manage, control and direct by corporate interests. That movement should be synonymous with Patient and Public Involvement in the NHS.

The term "service user" is preferred to "patient" because the term "patient" has, over the years, gathered role expectations which include subservience, passiveness, helplessness and ignorant - someone who has things done to and for them with no involvement of their own. "Service user" is one who uses services with a right to choose and provide their own input, in an equal partnership with the professional/clinician as an expert on themselves and their own circumstances.

PPI Forums with their statutory identity and powers established by the National Health Service Reform and Health Care Professions Act 2002 along with section 11 of the Health and Social Care Act 2001 should then offer huge benefits for the development of real service user and carer independence of thought, voice and action." ('PPI= Patient and Public Impediment', Mike Cox,

February 2004).

The Reference Terms.

1. What is the purpose of public and patient involvement?

1.1. "...in recent years, the needs, views and rights of NHS patients have rapidly ascended the political agenda, with the Government announcing in 2000 their "vision" of "a health service designed around the patient". While measures to improve access, convenience and quality of care for NHS patients form the mainstay of government policy, there have also been significant developments in terms of securing direct patient input into NHS services, and providing enhanced support to patients negotiating the NHS system...The role of PPIFs is to influence the day to day management of health services by the Trust, and to monitor the effectiveness of the PALS and ICAS in their area - be the main vehicle for the public to influence strategic priorities and day-to-day management of health services in their local area; be an independent critical friend on wider health matters in their community such as environmental health; review services from the patient perspective and monitor responses from local health services to complaints from patients." (Patient and Public Involvement in Health, Health Committee, 7th report, Session 2002-03).

1.2. "It is important to recognise that, for too long, decision making in the national health service has been behind closed doors and that all too often it has resembled a secret society rather than a public service. We have to open it up to all sections of society because the national health service does not serve just one part of the community; it serves the whole community and we must have a means of decision making that properly reflects all interest groups...The Bill strengthens the patients' voice inside the NHS. The CHCs had no role in primary care; patients forums will have that role. The CHCs were refused the right to inspect GPs' premises; patients forums will have that right. The CHCs were partly appointed by the Secretary of State for Health; patients forums will all be appointed independently of both the Secretary of State and indeed the NHS. The CHCs had no formal rights of representation within NHS organisations; patients forums will elect, as of right, one of their members to sit on every trust board. This is about not diminishing patients' rights in the health service, but increasing patients' rights in the health service" (Alan Milburn, Commons Hansard 2001).

1.3. In my opinion, the concept of PPI as outlined above is positive. it has

been the execution of the purpose which has been dysfunctional.

2. What form of public and patient involvement is desirable, practical and offers good value for money?
 - 2.1. It is clear that the structure of PPI should be democratic, service user led and run and “bottom-up”. It is a fundamental and very expensive mistake to try to impose top-down governance via corporate management structures.
 - 2.2. True independence is a basic requirement. For example, many PALS bodies only function partially because they are part of the trust organisation itself and are subject to both formal and insidious pressures to conform to the needs of the organisation.
 - 2.3. It is obvious that the use of volunteers offers good value for money. However, it is essential that volunteers are afforded full respect and full rights. I would say the resignation of 2248 volunteers from PPIFs by October 2005 (index 285 in the Dossier) was a reflection of the CPPIH’s regular mistreatment of its volunteers (141, 157, 169, and 177 of the Dossier amongst others).
 - 2.4. Finance should be arranged through a separate independent financial trust. Funding through local authorities means PPI having to conform to requirements written into contracts which could conflict with the objects of PPI - subtle ‘gagging’ clauses for example. Funding provided to local authorities by central government for PPI will, unless ring-fenced, proportionately disappear into other budgets. The same applies to NHS bodies.
 - 2.5. Standards in Public Life should apply throughout PPI.
 - 2.6. Public accountability must have clear, known channels and solid remedies. For example, it has been impossible to hold CPPIH to account for maladministration: a) referring unresolved complaints to the “parent body” (DH and Rosie Winterton) as advised by both the Office of the Parliamentary and Health Service Ombudsman and the Office of Standards in Public Life has just resulted in the complaint being passed back to CPPIH to deal with; b) referral to the Parliamentary Ombudsman has just brought a response that complaints cannot be dealt with because matters to do with CPPIH volunteers are judged to be “personnel matters” which, by law, cannot be dealt with by the Ombudsman. (Dossier: 103, 111, 179, 185, 191-201, 277, 280, 281, 287, 290, 291, and 292).

2.7. There is nothing wrong with the existing PPI Forums if they are organised in these ways, indeed, the stronger examples have set some standards which could be built on, despite CPPIH maladministration. Why waste money and throw away this hard earned fundamental learning?

2.8. Recommendations:

2.8.1. The body or partnership responsible for the governance of PPIFs should employ, or engage volunteer service users and carers as experts in their own right to oversee PPI, at every level, on an equal footing with all employed staff.

2.8.1. The body responsible for the oversight of PPI should be accountable to a Parliamentary Select Committee with a facility for direct referrals to that Committee by service users, carers and other members of the public.

2.8.2. There should be a change in the law to enable complaints by volunteers about PPI to be accepted by the Parliamentary and Health Service Ombudsman and not thrown out because they are “personnel matters” as is currently the case.

2.8.3. All personnel responsible for the governance of PPI should be brought under the remit of the Standards Board.

2.8.4. Any PPI organisation should have a clear and accessible whistleblowing policy with readily available links to whistleblowing bodies such as Public Concern at Work and Freedom to Care (Freedom to Care’s code on accountability should also be considered)

2.8.5. Volunteers should be brought under the ambit of the Public Interest Disclosure Act 1998.

2.8.6. Any internal complaints procedure should be carefully revised to simplify it and obviate possible misuses of power. An independent agency (e.g. the Healthcare Commission) should monitor second stage complaints.

2.8.7. Volunteers should be afforded the same protections as those in employment law and have the same rights as employees to have matters heard by an Employment Tribunal.

3. Why are existing systems for patient and public involvement being

reformed after 3 years?

3.1. The concept of PPI as outlined above and as in “Strengthening Accountability” is good. The installation and implementation by a top- down civil service management bureaucracy which ignored the thirty years’ plus expertise of service user organisations and individuals has been disastrous. We must learn our lessons from this.

3.2. Recommendation:

3.2.1. CPPIH should be immediately removed from the re-organisation process and this should be conducted by a federation of service users and carers.

4. How should LINKs be designed, including:

4.1. Remit and level of independence.

4.1.1. PPI Forums should remain, with their current remit, at the core with three completely independent clusters: local voluntary organisations; PALS; and ICAS. LINKs should be flexibly organised and responsible for their own local bottom-up planning, development and operational functions. Flexibility is essential to take account of the huge differences between metropolitan, urban and rural conditions. Rural policies must be “Rural Proofed”.

4.1.2. PALS has to be fully independent as the first line casework body - employment by NHS trusts inevitably potentially creates divided loyalties with most being resolved on the side of the body which pays the wages. There must be tight communication and operational LINKs between PALS and Forums.

4.1.3. See also 2.2.

4.1.4. Recommendations:

4.1.5. Process and meetings should ensure at least equal access to those living in rural areas. Positive discrimination in favour of those living in rural areas may be appropriate and required in some instances. All policies and procedures should be “Rural Proofed” as a matter of urgency.

4.1.6. *Where trusts cover large geographical areas a core and cluster approach should be adopted. There should be full local exploration of alternative means of attachment, i.e. ‘patient journeys’.*

4.1.7. *There should be avoidance of a position in which one person can dominate the team to pursue their own agenda.*

4.1.8. *See also 4.2.4.*

4.2. Membership and appointments.

4.2.1. Recommendations:

4.2.2. *Recruitment should be managed by a partnership between a National Federation of Service Users and the PPI Centre for Excellence.*

4.2.3. *Recruitment of volunteers should comply with the Investing in Volunteers Standard. Investing in Volunteers is being managed by the four development agencies of the UK Volunteering Forum: Volunteering England, Volunteer Development Scotland, Volunteer Development Agency in Northern Ireland, and Wales Council for Voluntary Action.”*

4.2.4. *In the interests of real PPIF independence and a minimisation of vested interests and conflicts of interests, the regulations should be revised to exclude any person with a continuing NHS or Social Services or other corporate commitment whether employed or not. There should also be a requirement for members to be publicly open and transparent.*

4.2.5. *The regulations should link to a freely and publicly available PPIF Code of Practice. There should be a review of the current membership with these changes in mind. that review should include and examination if para (3) (a) of the Membership and Procedure Regulations 2003 is being observed.*

4.2.6. *The parameters and regulations related to welfare benefits should be reviewed to minimise deterrents for service users’ and carers’ full involvement in PPI.*

4.2.7. *Recruitment and appointment procedures should record an assessment of prior experience and an assessment of prior learning for each member.*

4.2.8. *Recruitment and appointment processes should involve service users and carers.*

4.2.9. *The new governing body should, from the earliest date, individually engage existing forum members in an appraisal of present skills, knowledge, abilities and experience towards an assessment of immediate training needs.*

4.2.10. *The above appraisal process should be part of the recruitment and appointment of new members and should be conducted by the PPI Centre for Excellence.*

4.2.11. *Essential training needs should be met at the point of the appointment of forum members and there should be a secondary rolling programme of training which is regularly reviewed in partnership with the above organisations.*

4.2.12. *Education and training should be competent and rigorous continuous processes and not something tacked on as internal amateur activities by management and administrative staff.*

4.2.13. *All training and education processes should involve service users and carers.*

4.3. Funding and support.

4.3.1. Recommendations:

4.3.1.1. *In their 2001 document “Making it Work Together”, the Scottish Executive in the Section headed “Ideas on how to ensure independence”, said: “Keep funding at arms length by considering setting up an advocacy trust for your area - by pooling funding from different sources so no one agency holds the significant funding responsibility...” That concept should be adapted to LINKs.*

4.3.1.1. *Support should be provided by the Centre for PPI Excellence (knowledge, guidance, advice) and an integral part of LINKs providing administrative facilitation on the lines of the proven FSOs. Those FSOs which have proved to be dysfunctional (e.g. those who have imposed management decisions on Forums) should be excluded.*

4.3.1.1. *New organisations or groups used for PPIF facilitation*

should, wherever possible, be service user and carer run. They should take account of the special needs of rural areas.

4.3.1.1. *See also 2.4.*

4.4. Areas of focus.

4.4.1. Foci and priorities will differ according to the local needs, circumstances and social structures. They should be determined bottom-up by the LINKs themselves.

4.4.2. A special concern is that recent NHS re-organisation has created vast PCTs covering thousands of square miles (i.e. Norfolk PCT). Particular attention should be paid to the problems of how the 'local' element in LINKs can relate to these new leviathan like bodies, especially the planning and delivery of mental health and learning difficulties provision in primary care.

4.4.3. Recommendations.

4.4.3.1. *The building of LINKs should start from local community/neighbourhood level, and the term 'local' should be defined as such.*

4.4.3.2. *Consideration should be given to developing small 'portfolio' groups (e.g. mental health, HIV/aids, learning difficulties, drugs and alcohol) as PPI clusters in areas where one PCT covers a large geographical area.*

4.5. Statutory powers.

4.5.1. No change.

4.6. Relations with local health trusts.

4.6.1. Recommendation:

4.6.1.1. *There should be two PPIF **service user** places on each NHS trust board.*

4.7. National coordination.

4.7.1. Recommendation:

4.7.0.1. A National Federation of Service Users should be established to oversee PPI and advocate for volunteer rights. This should include existing Service user run organisations such as Shaping Our Lives, Together and MIND.

5. How should LINKs relate to and avoid overlap with:

5.1. Local Authority structures including Overview and Scrutiny Committees.

5.1.1. PPIF relations with OSCs are already good in some places. That should be enhanced by measures to ensure closer working between LAs and NHS being introduced elsewhere. The formation of LINKs should further strengthen relations.

5.1.2. The questions being asked are around how effective examination by OSCs is proving - where does it go from there in terms of addressing serious issues. As shown in the Health Committee interview with Rosie Winterton last year, referrals to her department appear to get lost in the in-tray.

5.1.3. Recommendation.

5.1.3.1. The legal powers of OSCs should be strengthened and shortened.

5.2. Foundation Trusts boards and Members Councils.

5.2.1. As in 4.6.1.

5.3. Inspectorates including the Healthcare Commission.

5.3.1. See 2.8.6.

5.4. Formal and informal complaints procedures.

6. 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?

6.1. Recommendations:

6.2. One model for consideration should be local high street shop front

premises for each PPIF with administrative and secretarial support on hand. This will maximise truly local involvement.

- 6.3. Activities should focus on processes rather than events. Reaching out to consult service users, carers and members of the public, especially those who are disaffected and those who have communication difficulties, should be a priority. Making decisions and taking actions based on forum members' opinions, however well informed, should be discouraged. There should be a focus on 'evidence based' processes.*
- 6.4. There should be a positive 'reach-out' policy as the primary activity of PPIFs and some elements of LINKs. Other agencies (i.e. drugs and alcohol services, Learning and Skills Department projects) have developed good practices here and PPI can learn from these. For example, small two person 'surgeries' in libraries, gp premises, hospitals, village halls, local pubs etc.*
- 6.5. PPIFs should be encouraged NOT to organise themselves as formal business committees. A 'team' approach operating on more 'organic' lines would seem more appropriate with team members taking on overlapping roles: i.e. liaison, local contact, advocacy, public speaker, etc.*
- 6.6. Norfolk County Council has published excellent disability guidelines for making public consultation possible "Accessibility Matters". PPI should use these.*

Mike Cox,
PPEyes,
2nd January, 2007.