**Patient Safety and the Autonomy of LINks**

**Remit and level of independence- and Its subversion by CPPIH.**

Independence

1. The autonomy of Patient Forums was embodied in the Statutory Instruments (National Health Service Reform and Health Care Professions Act 2002 Statutory Instrument 2003 No. 2123 & 2124) but these were subverted by CPPIH.

2. No budgets have been allocated to any Patient Forum. A formal response from the Health Committee is required. CPPIH withheld the money needed to do the job. A sum of at least £70 million has been improperly accounted. CPPIH has thus disqualified itself from taking any part in determining the form of LINks and this must be investigated.

3. In many parts of the country, particularly London, Forum Support staff did not accept direction from members as explicitly required by Statutory Instruments. Contact details with other Forums were deliberately withheld (again in violation of Statutory Instruments). It is not the case that Data Protection legislation requires this as CPPIH claimed.

4. CPPIH were aware of its non-compliance with the law. This produced many complaints about members who had criticised CPPIH. Members had no remedy and many resigned. The complaints code of practice was often breached by CPPIH itself. The contractual arrangements with Support Organisations and past CPPIH accounts must be subject to full forensic scrutiny so the mistakes of the past cannot be repeated.

5. In view of paragraphs 1-5 a National Body elected from Forums and LINks should be created with independent support and legal staff. A budget of £60,000 per annum should be sufficient per existing Forum as it is merged into LINks under Local Authorities. An annual subscription should be paid to the National body.

7. The existing Statutory Instruments were adequate and simply require strengthening in view of the experience outlined above of many, if not most, Patient Forums in the country.

Remit

8. The random unannounced Inspection visits to NHS premises is the single most important function of Patient Forums. In view of the difficulty of NHS staff complying with hand washing and other patient risk minimisation procedures (e.g. cleaning, control of nosocomial infection, patient nutrition, accurate and timely delivery of appropriate treatment) inspection procedures should be developed further.

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1 On 24th July 2005 I received an unsatisfactory reply from my MP Glenda Jackson and wrote:

"It seems to me the Minister’s response is wrong headed given the Statutory Instruments 2003 No. 2124 (Functions) and 2003 No. 2123 (Membership and Procedure) adopted by Parliament. Is there someone on the Health Select Committee and/or the Public Accounts Committee that might be prepared to listen seriously to Forum members given the链 of irresponsibility is established."

2 Michael English, chair of the London Region Patient Forum Executive, will present the “Dirty Dossier” of Dr Janet Albu, chair of University College Hospital Patient Forum, as part of his submission to the committee. This documents the abuse of the complaints procedure by CPPIH to silence its critics.
9. A model adapted from the Home Office funded Independent Custody Visiting Association, who visit custody suites in Police Stations to ensure proper treatment of detainees, could be applied.

10. No patient risk minimisation training was given by CPPIH and this gross deficiency should be corrected and enhanced for LINks with the right to inspect treatment records when Patient consent is given.

11. Training should be given to enable scrutiny of PCT expenditure and hospital accounts. This should be from the perspective of reducing preventable accidents and promoting error reduction in diagnosis and treatment.

12. Trusts should be able to give LINks members clear statistical evidence of beneficial outcomes for funded treatments.

13. This may be resisted because practitioners do not routinely acknowledge the general error rates in medical treatments.

14. 50% of Death Certificates are wrong (Sington and Cottrell³). Staff reported 840 lethal accidents to the National Patient Safety Agency in its first report whereas Sir Brian Jarman at Imperial College estimated 40,000 lethal accidents⁴.

15. The under reporting of accidents likely has its origins in unfair disciplinary procedures within the Healthcare professions that could also benefit from routine LINks scrutiny.

Membership and appointments

16. Existing arrangements from Statutory Instruments are satisfactory but potential conflict of interest by medical charity members and local authority Social Services must be open to full scrutiny.

Funding and support

17. Guaranteed funding at the rate of £50,000 per year per existing unmerged Forum with a subscription of £10,000 to a National LINks Body who will enforce standards of recruiting, reporting and training. LINks should report openly to anyone they wished and have full access to legal advice. Initiation of legal action against failing hospitals, contractors, practitioners etc should be considered. LINks Funding should be inflation index linked for around five years. Total costs are estimated at around £30 million per annum as with CPPIH. Support staff contracts should be subject to approval and monitoring by LINks.

Areas of focus

18. Patient safety concerns underlie every complaint that patients make. Authorities frequently deny this and the complainers are often labelled as malicious, litigious, neurotic and trouble-makers as the recent report by Action against Medical Accidents (AvMA) found⁵.

19. Unnecessary delay is also a major concern of patients with chaotic use of existing facilities maintained to feed the private sector and the waning status of the experts involved. Delay circumvents intelligent questioning of agreements to treat by patients. The negative and positive predictive value of diagnostic tests, for example, is rarely made known to the patient. Recent work at Arrow Park A & E Department on the “lean” approach is very encouraging⁶. Zero length queues without increased expenditure appears to be viable.

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³ http://jcp.bmj.com/cgi/content/full/55/7/499
⁴ http://www.ppif.org.uk/#in126
⁵ http://www.avma.org.uk/
⁶ "Redesigning the broken processes in the Health Service" http://www.ppif.org.uk/#in244
Statutory powers

20. Right to full inspection of all NHS premises and premises where NHS work is contracted must be re-enforced. Full access to all hospital records including financial, contractual and patient records where patient consent is given. The commercial confidence doctrine serves only to subvert Best Value and quality constraints.

Relations with local health Trusts

21. Regional Liaison Committees of LINks should be set up

National coordination

22. A National Body to regulate and develop activities should be elected from LINks members with a Board of Trustees. The Health Committee may care to consult further on this question.

How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees

23. Local concerns should be reported to Overview and Scrutiny Committees but LINks should be free to report to whomever they wish. All reports should be in the public domain with anonymisation if appropriate and be accessible on a central website- avoiding the appalling "Knowledge Management System" model of CPPIH whose user interface was so bad special training was required. A Wikipedia approach should be adopted.

Foundation Trust boards and Members Councils

24. LINks membership of boards and councils should be considered but the essential independence of LINks must not be compromised.

Inspectorates including the Healthcare Commission

25. The Inspectorates and Commission could develop inspection procedures for LINks with eventual ratification by the LINks National Board.

Formal and informal complaints procedures

26. Procedures should be monitored by LINks.

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?

27. As per legislation but LINks should insist on clear presentation of performance indicators to justify any intended reorganisation.
About me

28. I am Chairman of the Real Time Study Group, an academic and industry software design group set up in 1997 to examine the “Better Government” proposals. We criticised the lack of quantitative measures of accounting and performance in the proposals and subsequently presented a plan for better use of Information Technology to Treasury and Cabinet Office. Our approach of Alerting, Modelling and Real Time Audit (AMART), was subsequently reflected in the National Plan for IT (NPfIT). In common with the recent announcement at the Paris Global Public Policy Symposium by accounting firms of PwC, KPMG, Grant Thornton, BDO, Deloitte and Ernst & Young we recommend the real-time reporting of financial and performance data on the web7. When properly applied this will reduce error in the NHS. I am a fellow of the Cybernetics Society and member of the Council.

29. As a past member of Camden and Islington Mental Health Trust Patient and Public Involvement Forum I produced the Patient Public Involvement Organisation website in 2003. We focus on reducing error and delay in the NHS http://www.ppif.org.uk. We are informally governed by a Discussion Forum of some 52 self appointed public and patient users and take contributions from both Forum members and ex-Forum members from around the country. We publish Patient Safety oriented expert opinion from professional, academic and government sources. We summarise local newspaper reports of local Patient Forum activities. From our inception we have advocated a National Patient Forum Organisation.

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7 See http://www.cybsoc.org