

28th January 2005

Dear Sir or Madam,

Thank you for the opportunity to comment on the plans to replace the Commission for Patient and Public Involvement in Health (CPPIH). Action against Medical Accidents (AvMA) is an independent charity promoting patient safety and justice for people who have been affected by medical accidents. Since its inception in 1982 AvMA has advised and assisted in many thousands of NHS Complaints and worked closely with the NHS over improving investigation of adverse incidents and improving patient safety. Traditionally AvMA worked closely with Community Health Councils (CHCs) and more recently was involved in the work of the Transition Advisory Board advising the Department of Health on the transition from CHCs to the new system, in the pilot phase of the Independent Complaints Advocacy Service (ICAS). AvMA is still involved in the provision of specialist advice to an ICAS provider and their clients. The charity is therefore well placed to comment on the implications of the latest proposals for reform.

We are very disappointed that key decisions affecting the new system of patient and public involvement have already been taken without any consultation. AvMA is also concerned about the nature of the consultation that is taking place. Although we do not agree with everything which the CPPIH has done, we believe it is wrong to decide to abolish it without giving it a chance to prove its worth and without consultation with patients and the public. We have chosen to comment on the big issues as we see them rather than be constrained by the form used for the consultation. There are three main themes which we would like to emphasise:

- 1) AvMA is particularly concerned about the future of Independent Complaints Advocacy Services (ICAS). ICAS was a key component of the package to replace CHCs. The CPPIH has a statutory duty to set standards and monitor the quality of ICAS which is being usurped already. The 'provision' of ICAS is a statutory duty of PCT patient forums and yet there appears to be no intention or attempt to bring this into being.

As with other staff, the undertaking given by ministers was that CPPIH would employ the staff whose job it is to provide ICAS and deploy them to the PCT patient forums. As stated below, this role should be played by a new national body for patients forums or other bodies commissioned to provide the human resources/payroll function. It is wholly inappropriate that this role should be performed by the Department of Health itself, which is contrary to the legislation and commitments, and undermines the perceived and potentially the actual independence of ICAS, and its credibility.

Returning to the original model has significant benefits, including that the system would be more 'joined up' – patients forums would be able to hear about issues gleaned from ICAS from their own staff rather than facing the tensions that have been seen between contracted ICAS providers and patient forums. There would also be more opportunities for job diversification, peer support, and economies of scale through ICAS being provided by the staff teams allocated to PCT patient forums.

- 2) 'Forum Support Organisations' are an unnecessary extra tier of bureaucracy, and there should be a return to the original model of patient forums having their own staff allocated to them. This is not to say that no FSO's have done a good job within the difficult circumstances in which they are working. It is simply not tenable to have effective patient forums when the staff input has to be sought from a third party providing 'support' under contract. Forums need more than just administrative support and advice from third parties. They need staff to be part of their local patient forum and the wider movement and playing an active role in it (albeit being member-led), not simply 'hired help'.

It is this partnership between staff and members which made many CHCs very effective. It is needed to attract and retain a skilled and dedicated workforce to the movement and for forums to be credible and effective. By cutting out the third party organisations, it should be possible to reduce costs. The original plan, confirmed by ministers during the debates which persuaded parliament to allow the abolition of CHCs, was for the CPPIH to technically employ the staff and carry out the human resources/payroll functions, and deploy them to PCT patient forums to work with all forums in their area. This model could still work with the human resources/payroll function being taken on by a new national body for forums, which would be the best solution. Alternatively, this role could be commissioned from an existing body (even an NHS body provided there were sufficient safeguards to protect staff and forums from interference / guarantee their independence).

- 3) There is a need for an independent national body to support patient forums and represent them nationally. Ideally this would be a 'bottom-up' national association of patient forums. AvMA found the Association of Community Health Councils (ACHCEW) very useful partners at the national level in working for patients' interests. The new association could draw on the best elements of what ACHCEW did for the CHC movement whilst avoiding any of its weaknesses (such as its inability to insist on common quality standards).

It is possible that some of the existing roles of the CPPIH could be relinquished to other bodies (such as member recruitment and appointment), however consideration should be given to the new national body having all key roles in relation to patient forums.

As regards the proposed 'centre for PPI excellence', whilst there may be a role for a body to support and develop PPI across the NHS as a whole, this should

not be paid for with funds which were allocated specifically to pay for the system to replace CHCs. CPPIH budgets should be ring fenced purely for patient forums and their own national body, and the support of forums, including training, should come from their own national body.

We hope these comments are helpful.

Yours sincerely,

Liz Thomas
Policy and Research Manager