

Newsletter of the National Association of Patients' Forum

Members' Newsletter No 1. July 2007

1. The National Association

Members of the National Association were elected by members of Forums through an Electoral Reform Society ballot. There are two members for each Region whose names are shown on the enclosed contact list. We have so far had three national meetings and have been very active since the Association was established in May 2007. Some of our activities are shown below.

2. Our Goals

A copy of our initial three months programme is available on request. Our primary goals are to influence Parliament and the D of H to ensure an effective transition from Forums to LINKs, and to build a national movement of Forum members which will provide continuity for effective patient and public involvement in health.

3. Parliamentary work

A major area of work for the National Association has been to influence the Parliamentary process in the House of Lords (where the Local Government and Public Involvement in Health Bill has been this week) concerning the Government's plans to abolish Forum and create LINKs. We have held meetings with key people over the past few weeks both to influence them and to gain their support. We have had meetings with Meredith Vivian, the Department of Health's lead on the abolition plans (a report on this meeting is available from KMS: Shaping Health>PPI Forums>Forum Member Reference Groups>National Association Steering Group or from Ruth Marsden - contact details on enclosed list), Earl Howe the Conservative lead on health in the Lords and Baroness Neuberger the Liberal Democrat lead on health in the Lords. We have produced briefing documents for parliamentarians and many other bodies (see the above mentioned KMS container). We hope to meet Ann Keen, the new Health Minister holding the portfolio for PPI. She has replaced Rosie Winterton.

4. The Bill in the Lords - July 23rd

Members of the House of Lords formed a cross-party alliance to oppose and change key sections of the Local Government and Public Involvement in Health Bill. Baroness Meacher, Baroness Neuberger, Baroness Howe and Earl Howe are working closely to make a case against abolition of Forums and to substantially strengthen legislation on LINKs. They pointed out that the Bill was impossible to decipher, that the exact membership of a LINK was vague, that there was no definition of a LINK, that the functions were unclear and that the Bill was more concerned with process than functions. In response the Government said that they didn't want LINKs to have clear objectives, they thought they would create coherent arrangements for governance and would have a clear identity. The Minister also made it clear that LINKs could become charities, raise funds and that they would have minimal levels of support. The legislation is intended to be 'permissive' and local authorities are intended to take a view on the needs of LINKs. Ministers believe that the 'Host' will guarantee the independence of LINKs.

5. Meeting with Meredith Vivian - Key Points

We discussed major issues about the development of LINKs with Meredith and he has offered to communicate directly to Forums through this newsletter. Amongst the key issues discussed were the severe limits that will be placed on visits by members of LINKs to hospitals and clinics, the funding of LINKs and the gap between Forums and LINKs. As a result of this discussion we have written to Ed Milliband, Minister for the Cabinet Office about visiting rights and the Chancellor of the Exchequer, Mr Darling about funding and the gap. We will shortly be raising additional issues with the Chancellor about the lack of detail on the finances of LINKs - the funding formula, expenses, financial loss allowance, funding for access for disabled people, reaching hard to reach groups and the discrepancy between 'social-care' and 'health' remuneration-schemes for volunteers.

6. Amendments to Local Government and Public Involvement in Health Bill

We have drafted 23 amendments to the Bill. We were fortunate that one of our members, Michael English, is a former MP and therefore skilled in this work. Our amendments have influenced those put down by the Lords and the National Association has been mentioned in Hansard.

7. Our name

We felt that calling ourselves the National Association Steering Group was a bit loose and would not have made explicit to others who we were or what our purpose is. We decided to call the new body the 'National Association of Patients' Forums' steering group. This was necessary to give us a clear identity for all other agencies and individuals with whom we are dealing during this very critical period of the Local Gov. Bill and the proposed LINKs. We will put this decision of the Steering Group out for your views and ideas as soon as this initial frenetic period of work is over.

8. Local Authorities and the Formation of LINKs

Local authorities will be required to establish a 'host organisation' using money from the Government if the Bill goes through Parliament (it is expected to return to the Lords on October 8th, 10th and 19th). The 'host' will be like a Forum Support Organisation, but before it is appointed by the local authority the invitation to tender will have to be published as an advertisement in the European Journal. The whole process of competitive tendering will take anything up to six months. Local authorities will not know their budget allocations until November 2007, so it is impossible for LINKs to begin on April 1st 2008 and most estimates suggest that some time in 2009 is more likely. Therefore there will be no straight transition from Forums to LINKs. (The Department of Health view is that a seamless transition is unimportant.) Notwithstanding, National Association representatives have sent letters to the Chief Executive of every local authority in England with social services' responsibilities, pointing out that if Forums are abolished in March 2008, there will be no transition between Forums and LINKs. Our letter asked that they should support our position that abolition be deferred until the LINKs have been established in their area.

"We ask that as an organisation responsible for initiating arrangements for the future of independent patient and public involvement in health and social care, you make representations to Alan Johnson, the Secretary of State for Health, asking him to delay the abolition of Patients' Forums until the new LINKs organisations have been established and are operational."

9. Meeting of the National Association

We would like to plan meetings across the country to meet with Forum members, feed back to you and develop our strategy. Initially, we

envisage one meeting in the north and another in the south. Please let us know when and where you think would be best.

10. Meeting being arranged

We will shortly be meeting Jonathan Tritter, Director of the National Centre for Involvement (the NCI). This body has been established by the Department of Health to support the development of PPI in the NHS and to carry out assessments of the range of PPI documentation held by NHS Trusts and PCT. The NCI is expected to write the Regulations for LINKs and we are keen to find out what experience they have to carry out this work and to find effective ways for Forum members to work closely with the NCI. We met Jonathan Tritter recently at a Conference organised by the Socialist Health Association on the development of LINKs.

We will also be arranging, before the Bill return to the Commons, meetings with a wide range of MPs from all Parties including Patrick Hall the Chair of the All Party Group on PPI and the Conservative and Liberal Shadow Health Team.

11. The "Review of the NHS" by Lord Darzi - Health Minister

This was the subject of a joint press release between CPPIH and the National Association of Patients' Forums. We stressed that the 'review' would have little credibility without the inclusion of the views of patients and the public. Although Lord Darzi was asked to produce a preliminary report in the autumn to inform the Comprehensive Spending Review, his "Review" will run into the next year and we believe it makes sense to put the plan to establish LINKs on hold until his work is completed and has been subject to public consultation. We have written to Lord Darzi to make our view on this clear.

There is a separate plan for London which the new Health Minister appears to have had accepted by Central Government, without public consultation!

12. The Royal Colleges

Contacts have been made with the Royal Colleges of Medicine and the Academy of the Medical Royal Colleges. Their public relations offices/press offices have been approached and they have been provided with summaries of our concerns with the current proposals for LINKs. They will raise these issues in their own briefings of members of the Lords.

13. Other National Association issues

We are preparing a Manifesto as an interim document, pending the outcome of current legislation, and a Communications Strategy which is being used to facilitate and extend co-working and contact with all relevant agencies. Our next meeting will be held on 16 August 2007 in London.

Malcolm Alexander, Chair

Ruth Marsden, Vice Chair