



A STRONGER LOCAL VOICE

**COMMENTS FROM THE MOORE ADAMSON CRAIG PARTNERSHIP
ON THE CONSULTATIVE PAPER ON CREATING
A STRONGER LOCAL VOICE IN THE DEVELOPMENT OF
HEALTH AND SOCIAL CARE SERVICES**

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1. Background

The Moore Adamson Craig Partnership (M·A·C) welcomes the opportunity to comment on these proposals. We recognise the importance of putting patients and the public at the heart of the design and provision of services and the need to give people a “stronger voice”. Our experience of working with patients and the public, as well as with service providers, has shown us what can be achieved when this works well, but it has also highlighted the difficulty of making such involvement work.

We believe it is vital that the new systems and processes are made to work well this time round. In the past few years we have seen growing cynicism and in some cases real anger amongst those individuals who have given time and energy to Community Health Councils (CHCs) and Patient and Public Involvement Forums (PPIFs). In many cases this is matched by a weariness amongst even the most forward-looking service providers and commissioners who feel their organisations and their patients and the public have gained little from the shift from CHCs to Patient Forums. Some complain that their work with the public has been hampered and weakened, partly by repeated structural changes but more importantly by the alienation and subsequent withdrawal of individuals and organisations with whom they previously had positive working relationships.

The risks of getting it wrong this time are therefore very high. It is not only a question of making good use of public funds. It is also a question of resuscitating good will and developing positive new relationships. Our work over the past five years in the patient and public involvement field has shown us that the public in general and patients in particular are passionately committed to the idea of a publicly provided health service. They are strongly supportive of their local healthcare institutions at every level and the people who work within them. They want to be involved, but only in things which they see as being relevant to them. Where they have something to say they want to be listened to. They know they are really being listened to when they can see that their feedback has had an impact on the things that matter to them.

It is essential then that any new structures take full account of the lessons to be learnt from the successes and failures of user and public involvement within health and social care. It is equally important to learn from other sectors which have successfully engaged with their public.

A "patient-led NHS" will have little meaning for the users of health and care services unless they, carers and members of the public feel that they are involved with it in a meaningful way. Because health and social care are part of the same services from the users' perspective, what we term "patient and public involvement" must be a common theme across services and between sectors.



Patient, user and public involvement is nevertheless a means to an end. The real point of engaging users of the NHS is shared power in decision-making and genuine user-provider partnerships that improve things for all concerned. There are no short cuts or quick fixes to this end; involvement that does not lead in that direction is only a token gesture, and as such has little value.

On the following pages we respond to the specific questions posed by the consultative paper. We also raise some further questions which we believe will need to be addressed if the new structures are to succeed and put forward some suggestions as to possible approaches and solutions.



2. Question 1 – What arrangements can we put in place to make sure there is a smooth transition to the new system? How can we build on existing activity in the voluntary and community sector?

Change and transition are already an established fact of life and we doubt that actions taken some months hence – however inspired – can catch up with the gathering pace of the collapse of the previous arrangements .

It would fit in with a new and necessary mood of realism to acknowledge this. For too long this topic has been dogged by wishful thinking that ignored important realities about what was really going on in terms of the shortcomings of the present arrangements and the subsequent disillusionment of the volunteers who put themselves forward to participate in it. A new beginning must be signalled by acknowledging that what is done is done and that lessons have been learned. The need now is to develop and clearly define the role and purpose of these new bodies and establish governance and management arrangements which will make them successful and robust.

Now, there is a need to balance clear guidance and leadership from the centre with creating an environment where localities can develop new organisations and new relationships in ways which make sense to them. Time, careful thought and considerable co-operation will be needed if new structures and processes are to be successfully integrated with existing ones and those currently being developed.

LINks will need to focus initially on what it is that they are there to achieve rather than structures and processes. Local people as well as service providers will need to have a very clear understanding of the ends, rather than the means. Clarity about the purpose of the LINks and a realistic approach to what they can achieve, and within what timescales, will be vital to their success and to their ability to develop and sustain commitment and involvement from all parties.

It will be for individual localities (health organisations and local authorities working together) to identify the key link people and organisations. There should be an additional expectation that methods will be found for involving those organisations and individuals who might currently be defined by them as “hard to reach” by using developing new and different methodologies.



3. Question 2 – what do you think should be included in a basic model contract to assist local authorities tendering for host organisations to run a LINK? Question 4 - What governance arrangements do you think a LINK should have to make sure it is managed effectively?

We have taken questions 2 and 4 together since any contract must predicate the conditions that will govern the way its conditions will be managed and fulfilled.

The document speaks of some "statutory functions" but does not describe the networks as statutory bodies (as CHCs and then Patients Forums were). This will need clarification, especially as LINKs members could be both local voluntary organisations - some of whom may be health or social care service providers - and interested individuals.

At the heart of questions about governance is the question of who is in control of the LINK – who the 'moral' owners are. The paper is unclear about who will have ultimate control of the budget and therefore, in practice, who will control the activities. If funding is to come through the local authority it is vital that the governance arrangements create clear independence of thought and action whilst ensuring that the LINK is accountable for the money it is spending.

While no one wants a repeat of the shortcomings of many of the Forum Support Organisations, neither should these resources be handed over to local authority management without a wide ranging and open consultation by the local authority to identify the body most suited to develop the LINK, recruit and support its members and enable them to be effective. Also, LINKs should hold their own budget and decide their own staffing in order to avoid a repeat of major weaknesses of the present system. Promised guidance and a model contract must make this clear. Local authorities can channel the cash for LINKs, without the deduction of undue imposts in the name of 'management fees' before the remaining funds become available for their intended purpose.

As stated previously the staffing and management arrangements will need to be very clear in order to ensure independence. If there is a board/Council, who will appoint/elect the members? Will the board/Council be able to appoint/employ its own staff independently? We would argue that the success of the LINKs and their credibility will rely entirely on whether they are and are seen to be truly independent of service providers and commissioners. Such independence will not only depend upon structural arrangements, it will also require staff and members to have a very clear understanding of their roles and responsibilities. This will take clear guidance and training from the centre and some time to clarify and instil.



It is essential that these new bodies are and are seen to be independent of providers and commissioners of services. But they will also need to help their members (whether individuals or organisations) to have the capacity, knowledge and skills to secure real influence. Many of the failures of PPIFs were related to inadequate support both in terms of administration and in terms of expert guidance. We would hope that LINKs might end up looking not dissimilar to the very best of the old CHCs with an expert and professional staff supporting the membership.

We feel there is an opportunity for a radical new approach in this contractual area that starts not with the definition of the appropriate institutional relationships but with creating the space and the environment that will nurture and sustain the individual relationships.

As our initial remarks make clear, the people that suffered from the uncertainties and failures of the past were principally the volunteers, those members of the public, patients and carers who took part and responded to invitations to join in. (This is not to ignore the untimely job losses of CHC staff but their status as employed people ensured that they were not left wholly stranded.)

We therefore see the first priority to create the right conditions or contract to re-inspire, attract and retain the new corps of patient and public participants – to resuscitate that goodwill and develop those new relationships.

This person-centred contract would address the following issues:

- A right of audience and to be heard and involved
- Financial and other barriers to involvement
- The availability of incentives including payment
- The amount of training to be given to fulfil the role and to use all modern means of communication and association to do so
- Full technical support in modern communication channels especially low cost communications
- The availability of professional support at the times it is needed – eg weekend and evenings as well as daytime – a 0900 to 2100h day
- Support to include access to research studies and the funds and training to commission their own work
- The ethical and moral basis for the work and a code of expected conduct to be observed by all parties to the contract



- The basis for appraisal – how often and by whom and to what end?
- The degree of protection from legal action eg libel, negligent advice, etc.
- Accurate statement of the minimum/maximum time to be devoted to this work and the length of any engagement
- A means whereby volunteers can negotiate different terms of engagement and of reference to suit their circumstances.
- To have the power either to dismiss other contractors and service providers or vary their contracts if they not delivering the service demanded
- The power to move the closure of the LINKs if they are not performing and to allow others to bring such a motion so a fresh start can be made. We are not creating institutions that will last for ever – we are creating means to ends which if they do not deliver, we can try something else.

If a tendering organisation can show that it can devise a contract along these lines that can be incorporated into the 'main' host organisation contract and budget, then it is a serious contender to run a LINK regardless of whether it is a for-profit or not-for-profit organisation.



4. Question 3 - How can we best attract members and make people aware of the opportunities to be members of LINKs?

A good starting point will be the people who are already involved. PCTs and local authorities, as well as other key bodies such as hospital trusts, should be asked to publicise the existence of the LINK to their members and key stakeholders.

At this stage, national campaigns such as was run for PPIFs do not seem to us to be a good use of money. Word of mouth is very effective and all the key bodies should be encouraged to use their existing networks to develop links and seek members.

It is however essential that individuals in particular understand the purpose of the LINK and what their role will be. It is perfectly reasonable for people to ask “what is in it for me?” and for the LINK to be expected to provide a clear response. Individuals seek many different things out of this type of work and there will need to be an explicit recognition of this. For some it will be enough to know that they or their family may benefit directly from changes they are involved in bringing about. Others will expect more direct rewards.

Serious thought needs to be given to financial and other barriers to involvement such as expenses for travel, caring costs etc. Such costs should be reimbursed in a simple way and as immediately as possible. In some cases it may be appropriate to offer other incentives such as meals, training opportunities or even in some cases direct financial incentives, to the extent that this can be squared with benefit payments etc. We have found that these issues are of particular significance to the people whom health and social care services often find it hardest to talk to.

The timing and location of meeting and events is of key importance when trying to attract people to be involved. It is very easy to unwittingly create barriers to involvement by failing to recognise the limitations and restrictions on people’s time.

Experience shows that it is all too easy to make life hard for the individual or the small organisation who wants to make a contribution with all the usual administrative assault of rushed consultations, unrealistic timescales, and inappropriate demands on volunteer networks. Professionals must avoid both patronising and overestimating the capacity of lay networks. The latter is more dangerous as it leads to a culture of disappointment and failed expectations.



5. Question 5 - What is the best way for commissioners to respond to the community on what they should have done differently as a result of what they have heard? For example, should it be part of the proposed PCT prospectus?

It is certainly important, as we have already shown, for individuals and organisations involved in LINKs and also for the wider public to see that the LINKs have been listened to and their views taken on board. Equally it is important that when user and public views are put forward but **not** taken on board, commissioners explain why this has happened and present the evidence and views which have led to a different decision being made.

Rather than being restricted in the ways in which this should be done by having particular approaches specified (such as through the prospectus), LINKs should be asked to do this in many different ways depending on the issue and the audience. For a major consultation affecting many people it may be best to publish this widely, but for other groups and other issues it may be best to talk directly to those affected in whatever way they have told commissioners they are most comfortable with. Most important is for commissioners to be able to demonstrate when challenged that they have listened to the views of users and the public when making their decisions, however many people are affected.

If it is going to be heard and be seen to make a difference by generating evidence of its effectiveness, there are two key relationships to be developed and sustained: 1) with the Oversight and Scrutiny Committees and 2) with commissioners of health and social care. The first will be the advocacy platform to make a fuss and enlist political support. The relationship with the commissioners, however, will be different and we think more important, because it is much more focused on action, change and getting services right for local people. It is local people who pay for health and social care, so their voice in the commissioning and delivery process must be strong to be heard. That is the challenge for LINKs.

It is clear to us from our own work over a number of years in user engagement and from the views expressed to us by patients and the public that all sides need to work towards sustainable and ongoing relationships so that there is effective dialogue. Over time it is possible to develop relationships which mean that there are no huge surprises and all parties have an understanding of the limitations placed on them and the criteria on which decisions are based. Improved communications and better provision of information from providers/commissioners to LINKs and to the broader public should help to improve mutual understanding and promote the development of shared goals. There should therefore be greater demands on commissioners to publish and share information using the widest possible range of approaches. MAC Partnership will be commenting separately on the related proposals about “public petitions” raised in Our Health, Our Care Our Say and most recently in the Commissioning Framework.



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