



GMNA response to the four White Paper consultation documents.

Greater Manchester Neurological Alliance is an umbrella organisation of 26 voluntary neurological organisations working in Greater Manchester, (please see attached leaflet). Our member organisations are directly in touch with thousands of users of neurological services, and their carers.

We have been working for the past 12 years to develop a Neuro Network across Greater Manchester which aims to;

- *Improve the quality and accessibility of neurological services*
- *Promote the implementation of the National Service Framework*
- *Maintain and extend effective communication*

Our main funding is provided by service level agreements with the Neurosciences Network of the Association of Greater Manchester PCTs and The Neurosciences Centre at Salford Royal Hospital.

We have disseminated information about the white paper and consultations to all our members and have requested their comments on the draft GMNA response. These have now been incorporated into this final GMNA response. We have also encouraged each of our member organisations to submit individual responses.

General Overview

We welcome the White Paper's commitment to increased involvement of users, carers and clinicians in the commissioning of Health & Social Care Services but we think that insufficient recognition has been given to the considerable progress made with this in recent years. It is not true that GPs currently have no input into commissioning, of Professional Executive Committees within PCTs and there have been a whole series of requirements, both statutory and other, to involve users and carers in decisions about their care. Whilst agreeing with most of the objectives of the proposed changes, we are not convinced that they will achieve what is intended. We fear that rather there will be widespread disruption of services and a long period of uncertainty which will have significant costs in money, time and lost opportunities. Savings could be achieved without such widespread and radical changes.

In particular we wish to underline the significant involvement of users and carers across

the country in the standards for neurological care as set out in the National Service Framework for Long-term Neurological Conditions, and the danger of not incorporating these standards into any new frameworks. The personalisation of health care will bring dangers as well as new opportunities.

We are concerned about the intention to commercialise many aspects of the Health & Social Care services and fear that it could lead to disintegration of the NHS and less equality of access for users and carers, particularly those with Long term conditions. Our believe is that most users but particularly those with Long-term conditions are much more interested in good quality local services than in increased choice.

Our more detailed responses are given below. We have not set out to answer every point but have concentrated those most relevant to our client group. We feel that we have responded to the best of our ability considering the very short consultation period for such a large and complex document.

Commissioning for patients

1. It seems possible that there will be more GP Consortiums than there are currently PCTs. We feel that this would make it more difficult for small organisations such as GMNA to make their voices heard and have an influence in improving services. It has been difficult enough to spread ourselves across 10 PCTs and 10 Local Authorities.
2. We understand that GP consortia will only have responsibility for commissioning referrals to general neurology outpatients. It is difficult to see how hiving off one small part of a mainly specialised service can improve quality and effectiveness, (some GPs will have too little experience of neurological conditions, especially the rarer ones, to know what services need to be commissioned). In Greater Manchester, the North West Specialist Commissioning Team, PCTs and the Neurosciences Centre at Salford Royal, are engaged in an innovative programme to improve the quality of referrals to neurology outpatients. Who would have initiated such a programme under the proposed arrangements?
3. We are extremely concerned about the implications for quality and sustainability of services from pressures to consider 'any willing provider'. Cost rather than quality and local understanding may become the determining factor.
4. Although the proposal re: any willing provider may increase opportunities for the voluntary sector, we are concerned that the smaller organisations may find it harder to compete against both private and larger voluntary organisations for contracts and the choice of services provided could become more limited. Already smaller organisations have had their grants cut or reduced and therefore may not survive. Though the theory behind the proposals is to strengthen the voluntary sector and opportunities for local involvement, it could have the opposite effect,

unless infrastructure organisations like Greater Manchester Council for Voluntary Organisations (GMCVO) are funded to support joint/sub-contracting arrangements.

Local democratic legitimacy in health

1. The proposed plans make no mention of condition specific Regional Networks and localised Network Boards. Our experience is that Greater Manchester Neurosciences Network and Neurological Network Boards at PCT level have maintained pressure for improvement of services and created important opportunities for local involvement and co-operation. They will become even more important if the number of commissioning bodies increases. We believe that they should be preserved under any new arrangements.
2. We would welcome a stronger and clearer role for Health and Well-being Partnerships (which already exist in some areas and have experience of working across organisational boundaries). But
 - a) these boards will potentially have a lot of power but with limited experience of making difficult decisions about priorities. More information is needed about where they will look for guidance and how disputes will be resolved. We do not think direct referral to the National Commissioning Board will improve local democratic legitimacy.
 - b) a strength of LINKs was their clear remit to cover Health *and* Social Care and we are concerned that the new name (HealthWatch) does not reflect this wider remit
 - c) LINKs organisations appear to vary greatly in how effective and representative they are and some understandably fear further re-organisation. However, the new plans should provide an opportunity for re-commissioning where the current service is not working well, e.g. some existing LINKs organisations are duplicating/side-lining other organisations that already effectively represent the voices of users & carers. We also need further details about how this transition will take place.
3. The delegation of specialist commissioning to a National Board rather than SHA's and PCTs would not seem to be a contribution to local democracy. If there are to be regional offices we need to know more about these and what areas they will cover.

Transparency in outcomes

1. Though an outcomes framework seems to offer a rational approach to monitoring the quality and cost effectiveness of services, it is actually very difficult to apply to a group of users with long term, variable, progressive and mainly incurable conditions. In addition, desirable outcomes can be very specific to individual users for example, evidence of improved independence for someone with post head injury memory problems. Quality of life variables like empowerment and continuity of care are important to people with long-term neurological conditions, (see Integrated services for people with long-term neurological conditions: evaluation of the impact of the National service Framework, Social Policy Research Unit, University of York, 2010), and may be undermined by a more market orientated health service. Unless these points are taken into account, these groups of patients could suffer under the new set up. The objective to “support equality across all groups” would not be achieved.
2. There needs to be a better balance between monitoring outcomes and delivering services. We wonder who would make such decisions and who will actually provide the monitoring which has been proposed i.e. “regular publication of detailed performance data in an open and standardised format, on all healthcare providers”. Despite the many improvements in service monitoring implemented by SHAs and PCTs, there are still many gaps and inconsistencies. Much remains to be done and it is not clear who will have the experience and expertise to do this.

Regulating Healthcare Providers

1. We have already indicated our concerns about the regulation of GP Consortia and Health & Well-being Partnerships. We are not impressed by Monitor’s record of taking adequate account of quality & safety considerations in its Foundation Trust decisions, and would question the appropriateness of using such an economic model for vital public services like the NHS and Social Care. We do not agree that CQC should share responsibilities with Monitor as their priorities should be quite different.
2. We fear that pressure for the transition of Foundation Trusts into Social Enterprises would threaten the integrity or even the survival of the NHS.